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ABSTRACT

This document reports the proceedings of a summit to assess the adequacy of the U.S. effort to prevent mental retardation and related disabilities and to chart the course for future strategies to reduce the incidence and ameliorate the effects of these disabilities, particularly when caused by socioeconomic conditions. The document contains "Statement of Occasion: The Challenge" by Hugo Moser, a keynote address by Duane Alexander titled "A National Prevention Strategy for Addressing Conditions That Negatively Affect Mothers and Children," and an awards luncheon address by Louis W. Sullivan titled "Comments on the National Effort To Prevent Mental Retardation and Related Disabilities." The following papers are also included: "Impact of the 'New Morbidity' on Epidemiological Rates in Mental Retardation and Developmental Disabilities" (Godfrey Oakley); "Healthy People 2000 Objectives for the Nation--Impact on Persons with Mental Retardation and Related Disabilities" (Ashley A. Files); "A National Prevention Agenda Including the Institute of Medicine Study" (Allen Crocker); "A Model Approach for Preventing the 'New Morbidity': Implications for a National Plan of Action" (Alfred Baumeister); "Effective Strategies for Preventing Mental Retardation and Related Disabilities Associated with Socioeconomic Conditions" (Edward Zigler); "The Role of Developmental Disabilities Councils and Agencies in Planning for the Prevention of Mental Retardation and Related Disabilities" (Deborah McFadden); "Prevention Initiatives of the Administration for Children, Youth and Families To Address the Needs of Socioeconomically Disadvantaged Mothers and Children" (Wade F. Horn); "Support Services of the Maternal and Child Heath Bureau in Planning To Prevent Mental Retardation and Development Disabilities in Children" (Vince L. Hutchins); "Social Security Initiatives That Impact the Lives of Families at Risk and Reduce Children's Morbidity" (Gwendolyn S. King); "Rehabilitation Services Administration Options for Interagency Initiatives in Prevention and Rehabilitation" (Nell Carney); "Ameliorating the Effects of Mental Retardation and Related Disabilities in Aged Adults" (Joyce Berry); "NIDRR: Scope of Opportunity for Interagency Collaboration and Research in Mental Retardation" (William Graves); "Provisions of the Education of the

Handicapped Act--Part H" (Michael E. Vader); "Office of Special Education Programs: Coordinated Service Delivery for a Changing Population of Students with Disabilities" (Judy Schrag); "The Impact of Substance Abuse and Teratogenic Factors on Child Development and Family Options" (Judy Howard); "Professional Preparation and Training To Meet the Needs of Mothers and Children with HIV Infection and AIDS" (Herbert J. Cohen); "'Return Us the Children'--Societal Prerequisites" (Travis Thompson); "Florida's Movement from Prevention Planning to Prevention Program Implementation" (George Schmidt); "Iowa Community-Based Low Birth Weight Prevention Pilot Project" (Roger Chapman); "Getting the Lead Out in New Jersey: An Example of Interagency Leadership and Cooperation" (Deborah E. Cohen); and "California--Addressing the Needs of a Changing Society" (Raymond Peterson). The document also contains summaries of work group recommendations and administrative items related to the summit. (JDD)

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Summit on the National Effort To Prevent Mental Retardation and Related Disabilities

Summit Proceedings

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
President's Committee on Mental Retardation

SUMMIT ON THE NATIONAL EFFORT TO PREVENT MENTAL RETARDATION AND RELATED DISABILITIES

Summit Proceedings
February 6-7, 1991
Washington, DC

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PREFACE

To the nation's capitol, during brisk mid-winter days, they came: heads of Federal agencies, representatives of Governors' offices and Developmental Disabilities Planning Councils, health officials, prevention planners, service providers, consumer advocates, educators, researchers and legislators. They came from thirty of the continental United States, the District of Columbia, South Africa, Saipan and Mariana Islands. This international, interdisciplinary gathering of colleagues came to the February 5-7, 1991 "Summit on the National Effort to Prevent Mental Retardation and Related Disabilities" from many different places, but with a "single mind." They came to assess the adequacy of the national effort to prevent mental retardation and related disabilities, and chart the course for future strategies to reduce the incidence and ameliorate the effects of these disabilities, particularly when caused by socioeconomic conditions.

The Summit provided a forum for the sharing, "show 'n' tell" style, of national, Federal, state and community prevention exhibits. It also provided a forum for recognition, by Louis W. Sullivan, M.D., Secretary, U.S. Department of Health and Human Services, of the outstanding contributions made to the field of mental retardation and related disabilities by four distinguished individuals and a state Developmental Disabilities Planning Council. Noteworthy is the fact that the Summit facilitated interdisciplinary efforts of professionals and constituency groups to contribute to the early development of a comprehensive national plan of action capable of significantly minimizing the occurrence of mental retardation and related disabilities by improving options for mothers and children.

This working Summit featured provocative technical papers delivered by renowned leaders in the field; stimulating work group sessions that addressed key issues that impact on prevention initiatives at the national, regional, state, and community levels; impressive deliberation, by agency executives, of interagency approaches and options to prevent disability; and practical recommendations that are both realistic and achievable..

You are invited to carefully peruse the contents of this summit proceedings document, seriously consider ways in which you may be an active participant in the national effort to improve options for mothers and children, and share your candid comments regarding the resourcefulness of this publication with members and staff of the President's Committee on Mental Retardation.

SUMMIT ON THE NATIONAL EFFORT TO PREVENT MENTAL RETARDATION AND RELATED DISABILITIES

Opening Plenary Session
February 6, 1991

Welcome
Greetings
Statement of Occasion
Keynote Address
Awards Luncheon Address

WELCOME

by Albert L. Anderson, D.D.S.
Vice Chairman
President's Committee on Mental Retardation
San Diego, California

I would like to welcome you to this Summit on the National Effort to Prevent Mental Retardation and Related Disabilities. I want to first bring you greetings from Dr. Bill Hummer, who has done such a magnificent job of putting this conference together. You know, Bill has served as Chairman of the National Coalition on Prevention of Mental Retardation for many years, and unfortunately had a very serious family emergency that prevented him from joining us for the Summit. He sends his best wishes to you. Bill is Chief of Staff at St. John's Hospital in Los Angeles.

I think that all of you know the background and purpose of this meeting. The bottom line is prevention and amelioration of the effects of mental retardation and related disabilities. I am very pleased this morning to have with us my boss, a person for whom I have tremendous respect. Mary Sheila Gall has been an Assistant Secretary who has greatly facilitated success in the PCMR's accomplishment of many program initiatives that minimize the occurrence of mental retardation. She was sworn in as Assistant Secretary for Human Development Services in 1989, having come to HHS from the Office of Personnel Management where, since 1986, she served as Counselor to the Director. In August of 1987, she was named Chair of the President's Task Force on Adoption which identified barriers to adoption and explored methods to promote adoption. During the period 1981 to 1986, Ms. Gall was Deputy Domestic Policy Advisor in the office of Vice President Bush. She was born in Buffalo, New York. She received her Bachelor of Arts degree from Rosary Hills College in Buffalo in 1971. She is a single adoptive parent of two children with developmental disabilities.

We are very proud of her, and pleased she is our Assistant Secretary. Please welcome Mary Sheila Gall.

GREETINGS

by Mary Sheila Gall
Assistant Secretary
for Human Development Services
Office of Human Development Services
U.S. Department of Health and Human Services
Washington, D.C.

Before I begin, let me just take a moment to thank Dr. Anderson, not only for the work he has done with PCMR and for this administration, but also for his many years of tireless service to the children in his community. Dr. Anderson is truly what the President considers a bright and shining point of light.

This is a terrific turn-out. We are very pleased. We have over 30 states represented. We have with us today, representatives of several countries who are very interested in preventing mental retardation and related disabilities. I want to thank Dr. Banik, Executive Director of the PCMR, and his staff for all the hard work they have done in putting this conference together. Dr. Hummer and the members of PCMR are also to be commended for all their tireless efforts in the area of prevention.

This theme of preventing the "New Morbidity" is very important to the President, and it is very important to our Secretary, Dr. Louis Sullivan. As a matter of fact, the Secretary will be joining you today for lunch. The President asked him to go to Haiti this morning to represent him during the course of a couple of days of activities, and Dr. Sullivan specifically said he would not leave until after he had time to spend with Summit participants today because he is very interested in issues related to prevention of disabilities. It is one of his more significant themes that is highlighted throughout the entire Department of Health and Human Services.

Prevention is a very important issue for all of us in Human Development Services (HDS). We deal with a whole host of issues including child welfare issues, foster care and adoption, and developmental disabilities. We administer the Head Start program, Native American program, and Senior Citizen programs. The significance of what you are discussing for the next couple of days plays a very important role in the kinds of programs that we are in the process of developing. You are going to be discussing a lot of important themes, including options for maternal and child health, teen pregnancy, and substance abuse. All of these issues ripple throughout our programs in HDS, whether we are talking about Head Start families who have an increasing substance

abuse problem and how we craft programs to address those problems, or runaway youth where we provide shelter, care, and counseling for them. I believe that the lessons that we learn at this Summit from all of you, and the information we can share with you, will have a significant impact on the programs we are administering at the Federal level; programs that you are seeing at the state and the local level, and in the private and the public sector.

Like you, I deal with these issues on a daily basis, and I deal with them on a personal level. I have two of the greatest kids in the world who have significant, very special challenges that they have to meet every single day, and I am very proud of the way in which they deal with those challenges. But I know first hand, as a parent, what it is like to go to the educational system and to demand the services that my children need. I know what it is like to be told "your child is not eligible" for one reason or another, or "we do not have the funds" for a program for the child down the street who has Down's Syndrome and needs special therapy. I know what it is like to go to the county, and to go to the state and make those demands, and fight those battles with other parents.

I guess it saddens me more than just about anything else because I know that some of this could be prevented. That is why your contribution here today and tomorrow is so important in helping our children and our families. Our programs are becoming increasingly responsive to our families in dealing with the day to day issues with which they have to deal. You will hear more about that as members of the HDS family talk to you. You will hear about our programs for seniors with Joyce Berry; Wade Horn will be talking about our children and family programs; and Debbie McFadden will be talking to you about some of the Disability Council activities that are being implemented. We are really intensifying our efforts to help children and families deal with the special challenges that they have.

One good example is in the Head Start program. We have Dr. Ed Zigler, one of the fathers of Head Start, as a presenter on the Summit agenda. Dr. Zigler has worked tirelessly in the development of Head Start. We are making significant changes in the Head Start program to address not only the expansion of additional children coming into the program, but also expansion of services to Head Start families. About 20 percent of our Head Start families have a significant substance abuse problem, and we observe that the number is increasing. We also know that our families have problems with employment and leisure, and so we are establishing special services across the country to address those issues.

Substance abuse, of course, has a tremendous impact on the child welfare system. We are therefore crafting responses at the state, local, and Federal levels to address that

issue as well. Prevention of these conditions is Dr. Sullivan's theme. It is also the President's theme. We see the priority that is given to prevention activities as we look at the new budget for maternal and child health efforts and other related activities within our department. We expect to learn a lot from you, and I hope that you can learn something from us as well. What you do the next couple of days will have a tremendous impact on children and families. For that, I thank you very much.

STATEMENT OF OCCASION: THE CHALLENGE

by Hugo Moser, M.D.
Director
Center for Research on Mental Retardation
and Related Aspects of Human Development
Kennedy Institute and Johns Hopkins University
Baltimore, Maryland

My greatest thanks for being asked to give this challenge. It is a challenge to you and to me also.

It is particularly pleasing to have here the chance to meet again several people who have been my friends and role models for a long time, in particular Dr. George Tarjan and Dr. Ed Zigler.

With the first slide, let me begin with the opening of the Kennedy Institute in Baltimore in January of 1988. At that time, Secretary of Health, Education and Welfare (HEW), Wilbur Cohen, was the main speaker. Here is Dr. Cook, who really started so much of everything that is going on here. Dr. Fred Richardson, the first director of the Kennedy Institute. Secretary Cohen gave a speech which I thought was very important and meaningful. He entitled it "A Proof and a Promise." The proof was the creation of the Institute itself which was a product of Public Law 88-164, the 1963 Mental Retardation Center Construction Act. The promise was that programs in this area would exist and continue to exist, of course, under the University Affiliated Center Program and the mental retardation research centers.

But in addition, he made a remark in this speech which I think is important and ties us to the present. He indicated the significance that the center was located in a disadvantaged area of Baltimore, and he pointed out how appropriate it was for the training and research center to be located in an area so much at risk for mental retardation and an area that would now be considered the equivalent of "The New Morbidity". Also, I wanted to report that I believe the Kennedy Institute has adhered to the Secretary's admonition.

As an example of this, on July 27, 1990, the Institute, along with five other groups, requested the use of a school building, the Fairmont School, which was a former high school, located four blocks away. The building was available for one dollar. There was a great deal of competition for the site and I believe it is due to our Institute's

community involvement that Mayor Kurt Schmoke did assign that site to us, and it gives us the opportunity to participate still more effectively in the efforts to overcome the New Morbidity.

I must admit that this selection was not universally applauded. The director of the Citizens for Washington Hill Community Group said that she was disappointed but not surprised at the selection, and that there would have been a more favorable impact if other applicants had been selected. I show this slide to emphasize the need for a meeting like this and our need for advocacy. I am proud to report that Dr. Peter Fanning, who leads community relationships at the Kennedy Institute, has worked very effectively with the Washington Hill Community Group and has now earned the enthusiastic support of the community.

I would then like to state what I consider the main challenge: We must convey to the public the power and humanity, the necessity, and cost-effectiveness of what we already know, and the excitement of what we can learn in the next decade. I have a few slides in which I present some of my own thoughts about the power and the excitement for the next decade. Some of them may be "pie in the sky" but I think we are supposed to dream a bit.

As examples of present knowledge, I believe that the concept of the New Morbidity is perhaps the most important new knowledge. It is the identification of interlocking socioeconomic behavioral and biomedical risk factors and the demonstration that they can be alleviated by cost effective intervention. I believe that is the main message that I feel our group ought to convey to the public at-large.

I have one example which Dr. Craig Ramey gave me permission to use in an article about to be published in Pediatrics. It reflects the program supported by the Robert Wood Johnson Foundation, the National Institute of Child Health and Human Development (NICHD), and the Maternal and Child Health Service which provided behavioral, educational, and social intervention in children with low birth weight. It is an exciting example of the application of the New Morbidity concept. These children, at increased biological risk of mental retardation, were helped decisively and effectively by socio-behavioral intervention. I should add that it is my own view that it is crucially important that longer follow-up be provided for these children. In addition to these short-term gains, we need to know the eventual long-term outcome.

Another example of present knowledge is the successful design of a "scorecard" to track the incidence of various forms of mental retardation, which has been developed by Dr. Godfrey Oakley at the Centers for Disease Control (CDC) and is being applied in

the Atlanta area. Unless we have a national scorecard for the various conditions, we will never know which of our programs are effective.

Another outstanding example is the successful organization and implementation of some statewide programs for the prevention of mental retardation. This has been a major objective and is an outcome of national prevention efforts that represent coalitions of many organizations. Dr. Alan Crocker has been particularly active in this organization; and the CDC has a major role in the development of these statewide programs which, again, are crucial efforts in implementation.

Other examples of the application of present knowledge are the identification of environmental toxins, lead and others; the very great success of immunization programs; the recent promise that the new vaccine for H-influenza meningitis will become effective; and the metabolic screening programs for hypothyroidism, phenylketonuria (PKU) and neural tube defects.

I recently reviewed the 220 metabolic disorders that we know cause mental retardation and to my surprise and pleasure found that for 65 of them we can, even with present knowledge, make a significant impact. This shows that we are not as powerless, even with these admittedly difficult disorders. And then gene therapy has begun.

Finally, I want to highlight some of the advances that I think can happen during the next decade. I would like to make a plea for precision of diagnosis. We now know that there are more than 1,000 separate causes for mental retardation. We need to insist on the same degree of diagnostic accuracy as we now take for granted, say, in heart or kidney disease. Nobody would accept now a days that statement that the patient has a "heart problem but we don't really know why and what does it matter anyway." Yet for mental retardation, this attitude still flourishes. I believe the point has come that we can take an active stance and insist on correct diagnosis, both because of the practical implications and because of the symbolism that we leave behind be the therapeutic nihilism which has too much applied to this field.

Secondly, I believe that during the next decade or perhaps a bit longer, all of the major causes of genetically determined mental retardation will be identifiable at the gene level with deoxyribose nucleic acid (DNA) studies. The implications of this are very hard to come to grips with. It will introduce an entirely new approach in respect to diagnosis and prevention. Gene therapy will become possible for some of the genetic causes of mental retardation.

Another area that I am very excited about is that there are efforts which I believe will be successful to reduce the devastating effects of brain oxygen deprivation. At present, four minutes of oxygen deprivation to the brain leads to irremediable damage. If this can be ameliorated, the benefits in respect to perinatal damage and the effects of drowning would be incalculable.

Finally, I believe it will become possible to understand the biological basis of learning disabilities. In the field of vision, that has been determined, but I believe that the environmental, biological interactions which, if you will, are the basis of the New Morbidity, will become decipherable and that will have major effects on our ability to prevent and treat mental retardation.

I would like to leave with these three thoughts. One, mental retardation is a moving target. We are now able to prevent mental retardation due to thyroid lack. We are beginning to make a major impact on neurotube defects, and we have made a major impact on immunization. But as we are doing this, our target is moving. We now have the new issues of Acquired Immune Deficiency Syndrome (AIDS) and drug addiction. The point I am making is that we cannot rely only on applying what we know. We have to continue to be ready through research to meet these new challenges.

Secondly, I would like to quote a statement made by Murray Sidman -- that we develop methods so that we can learn by trial without error. Error has a devastating effect and there are a number of conditions where an error, even one, can never be overcome. Think about AIDS and crack. So, the idea of developing behavioral methodology of learning by trial without error is a concept that I believe we ought to foster.

Finally, the scope of the field of mental retardation is overpowering. I came into it as a very innocent person working on the biochemistry of medichromatic leukodystrophy and was swept into a field, the breadth of which no one person can grasp. We are totally dependent on multiple disciplines, perhaps more than any other field I know. Again, this epitomizes the meaning of this conference, namely the understanding and the application of the concept of new morbidity. Thank you.

KEYNOTE ADDRESS

by Duane Alexander, M.D.
Director
National Institute of Child Health and Human Development
Bethesda, Maryland

Giving this keynote speech here today reminds me of one of my favorite restaurants in Colorado called the Bayou. In the heart of the Rockies is the last place you would expect to find this Cajun restaurant. It features blackened redfish, Cajun froglegs, swamp and moo (combination shrimp creole and blackened steak), and other spicy Cajun dishes in an atmosphere that's informal at best. On one of my first visits there I asked the owners, who were young ski-lovers, why they opened a Cajun restaurant in the Colorado Rockies. Their answer was straightforward--"We tried Italian and that didn't work, then we tried Chinese and that didn't work, so next we tried Cajun and that worked." A couple weeks ago when I was invited to give this keynote address, I asked "Why me?" and the answer was straightforward--"Well, we asked the Secretary, and he was only available to speak at lunch, and we asked the Surgeon General, but she was out of town, so we were desperate and thought we'd try you."

So right away you know I have no delusions about being an overwhelming first choice. On the other hand, Dr. Sullivan and Dr. Novello are pretty impressive choices to serve as backup for. So as backup I'll do the best I can to give you some Cajun blackened redfish that you'll long remember. (I hope in a positive sense of wanting the recipe instead of suffering indigestion.)

I was asked to speak about a national prevention strategy for addressing conditions that negatively affect mothers and children, specifically those conditions that lead to Mental Retardation and Developmental Disabilities
don't have to start from scratch to develop that strategy. We have a heritage from our predecessors in the MRDD field that has already put us on the road to achieving the goal of major reductions in the incidence of MRDD by the end of this century. Some of you in this audience have marched on that road from the beginning, but many others are relatively new to this field. For this new generation in particular, I would like to take just a few minutes at the outset to describe where we have come from and how, and thereby

provide an appreciation of the progress that has been made; then sketch out a vision of what can be anticipated from research, and finally, lay out a challenge for what we need to work on to realize the full potential of what science and society can do to prevent or ameliorate MRDD.

In some ways it is fortunate that only a few of you here do remember firsthand what the field of MRDD was like in the 1950s and can appreciate how it has changed. At that time institutional care for retarded or disabled people was the rule; the little research that was done was conducted mostly at these institutions, out of the mainstream of medicine, and the quality was generally second-rate at best. The leading visionary at that time for improved research and care for MRDD persons was Dr. Robert E. Cooke, Chief of Pediatrics at Johns Hopkins and the mentor for many future professionals in this field, myself included. With the election of his personal friend John Kennedy to the presidency in 1960, Dr. Cooke had the opportunity to implement his vision for improving the lives of MRDD people. There were four components to his plan:

- Provision of Federal funds for construction of University Affiliated Facilities (UAFs) at colleges and medical schools to apply academic expertise to develop and demonstrate improved methods of care for MRDD persons and train medical and related professionals in that care.

- Federal funds for construction of Mental Retardation Research Centers (MRRCs), again at medical schools and universities, to get research in this field moved out of institutions and into the mainstream of science, and place these persons on an equal footing with other subjects of human scientific investigation.

- Establishment of a new institute, the National Institute of Child Health and Human Development (NICHD) at the National Institutes of Health (NIH), to serve as a funding source for this research and the MRRCs, and again place it on a par with other areas of science.

- Establishment of a committee by the President to provide ongoing national oversight of the effort to prevent MRDD and improve the lives and treatments for persons with MR. The President's Committee on Mental Retardation (PCMR) established by Lyndon B. Johnson, whose 25th anniversary this conference commemorates, was the permanent successor to the original advisory committee established by John F. Kennedy.

All parts of Dr. Cooke's program were enacted by Congress at the urging of President Kennedy, and the changes in the 28 years consequent to that action have been

profound for science and society. Both MRDD persons and MRDD research have been deinstitutionalized and mainstreamed. New facilities for treating MRDD persons have been built that are second to none. Research on MRDD is presented at the most prestigious scientific meetings, and most important of all, that research has made a difference. Thanks to some of that research, every year in the U.S. we prevent:

- 250 cases of MR due to phenylketonuria (PKU) by newborn screening and dietary treatment;
- 1,000 cases of MR due to congenital hypothyroidism thanks to newborn screening and thyroid hormone replacement therapy;
- 2,000 cases of MR or deafness by use of Rhogam to prevent Rh disease and bilirubin encephalopathy;
- 3,000 cases of MR due to measles encephalitis thanks to measles vaccine; and
- untold numbers of cases of rubella encephalopathy thanks to rubella vaccine.

Thanks to this research we have improved ways to manage head trauma, asphyxia, and infectious diseases to reduce their adverse mental and physical sequelae. We have more effective approaches to physical rehabilitation, speech therapy, and teaching skills of daily living. We are more effective at incorporating physically and mentally handicapped students into the regular classroom and into the community, and we have new devices to assist that process. Early intervention programs with high-risk infants and children have shown remarkable results in reducing the predicted incidence of subnormal intellectual functioning. New causes of MR have been discovered--Fragile X, Rett's, Fetal Alcohol Syndrome, and Urea Cycle Disorders, to mention just a few--and new attempts at treatment are being developed and assessed. And leading the way in all this research have been the NICHD and MRRCs.

These projects have all, in their own small way, made a difference, but the battle against MRDD is far from over. They have not turned the tide, because no tide was even flowing. But they have started a tide, which is flowing slowly, and holds promise for a flood if we are able to take advantage of our opportunities. Let me tell you about some of the opportunities now being pursued, and share with you the excitement of the promise that is to come.

Current Projects

H.flu vaccine. Of all our current projects, the one with the most imminent payoff is the development of a conjugate vaccine against H.influenza. Meningitis, due to this bacterium, is the leading cause of acquired MR in children in the U.S., with 18,000 children infected and 3,000-4,000 left permanently retarded or deaf per year. Some years ago an NICHD intramural scientist, Dr. John Robbins, demonstrated that the polysaccharide coat of the bacteria provided a safe, cheap, effective antigen for a vaccine. The vaccine he developed and tested clearly worked for children over age 18 months, but not in infants where three fourths of the disease occurs. In 1980, Dr. Robbins developed the concept of a conjugate vaccine, in which the polysaccharide is linked to a protein, such as diphtheria or tetanus toxoid. When this is done, even young infants are protected by the vaccine. Two H.flu conjugate vaccines have been licensed by the FDA in the last few months, and two others are currently in the licensing process. The disease is already disappearing in communities where the clinical trials have been done. Routine use of H.flu conjugate vaccine given at the same time as infant DPT shots (2-4-6 months) will nearly eliminate H.flu meningitis as a cause of MR and deafness. If you want to take back to your states from this conference one effective new intervention to prevent MRDD, go back and get this new vaccine used starting at two months of age.

Tin Protoporphyrin. Another exciting area with potential broad application is a new means of preventing hyperbilirubinemia (severe jaundice) in newborn infants and the brain damage that can result. We used to do blood exchange transfusions, and now use bright lights in the newborn nursery to keep bilirubin levels within safe limits. Scientists have recently developed a new approach--inhibiting the enzyme that breaks down hemoglobin from red blood cells to form bilirubin. One or two injections of this enzyme inhibitor, tin protoporphyrin, may protect an infant until its enzymes mature and it can remove the bilirubin itself. We are presently testing this approach in a clinical trial.

NMDA Receptors. Basic science continues to play a key role in MRDD research, as in all fields. A beautiful example of current basic science research with clinical payoff just over the horizon is the work with glutamate and the NMDA receptor. Scientists studying normal brain mechanisms have found receptors on neurons termed "NMDA receptors," that are triggered by glutamate, a neurotransmitter that regulates the flow of calcium and other ions into the cell and normally plays a role in memory formation. But in conditions of reduced oxygen, such as a stroke or difficult infant delivery, excess glutamate is released and floods the NMDA receptors so that too much calcium enters the cell, killing the cell. Scientists have developed drugs that block the action of glutamate on the NMDA receptor, and demonstrated in laboratory animals that the drugs protect against

hypoxic brain injury. Work is going on to develop and test drugs that will have this function and protective effect in humans.

Down's Syndrome. In other research made possible by the new tools of modern genetics, we are learning more and more about Down's syndrome. It was not until 1959 that we knew it was caused by an extra chromosome 21. In the last few years we have learned that it is not the entire chromosome 21 that causes the syndrome, but the genes in a narrow segment called Band 22 at the far end of the long arm of that chromosome. Scientists are now mapping the genes in that region to learn what they are, what they do, and how they produce the anomalies of Down's syndrome. With the probability that just one or a few genes rather than the whole chromosome produce the syndrome, the possibility of therapy for the syndrome becomes more likely.

Nutrition. Diet modification was historically one of the first successful approaches to preventing MR, with the provision of a low-phenylalanine diet to infants born with PKU. Dietary approaches are currently being applied by NICHD-supported scientists to try to prevent several MR-producing disorders. One is maternal PKU. There we are paying the price for our success. Girls born with PKU who would have been severely retarded and childless are now, thanks to newborn screening and dietary treatment, normal adults who are having children. The high phenylalanine level in pregnancy is toxic to their developing fetus, and most of their children are born retarded. NICHD is supporting a clinical trial assessing whether re-institution of the low-phenylalanine diet in early pregnancy will protect the fetus. Early results look very promising, and the trial is continuing. Some of the urea cycle disorders show promise of responding to dietary or chemical treatments. Patients with another disorder, adrenoleukodystrophy, are being studied by Dr. Hugo Moser to assess whether a diet high in glycerol tri-erucate, a long-chain fatty acid, will slow or halt the progression of their neurodegenerative disorders, again with early indications of success.

Early Intervention. Behavioral studies also show great promise for modifying or alleviating some of the commonest forms of MRDD. Recent publication of the results of the Infant Health and Development Program, an early intervention study based on the results of years of NICHD-supported research, give a clear indication that intensive early interventions with high-risk infants markedly raise intellectual performance, reduce the prevalence of functioning at the MR level, and improve behavior and social skills at age 3. We at NICHD and the Maternal and Child Health Bureau will be funding the follow-up of these children at age 6 and 8 years. What remains is for society to apply these lessons learned on a large scale. Science will not have really done its job until these results from research are translated into practice. Of all the studies that NICHD

has supported, this one has the greatest potential numerical and economic effect in preventing MR.

Future Research

What about future directions in MRDD research? Talking about this is very risky, because science is moving so fast that what you call the future often turns out to have been done yesterday.

Gene Therapy. A case in point, and one of the most exciting frontiers ever in medicine, is gene replacement therapy. The future is here, and you in this field of MRDD have the good fortune to be right in the middle of it. On Thursday, September 14, 1990, at the NIH Clinical Center in Bethesda, a 4-year-old girl with Severe Combined Immune Deficiency (SCID) became the world's first patient to have her disorder treated with gene replacement. Doctors earlier had removed some of her blood, separated out the white blood cells, and used a virus vector to carry into those cells the gene for making the enzyme adenosine deaminase (ADA) that she was born without. The gene entered the DNA of some of those cells and started producing ADA. Last September 14 those cells were injected into the patient, and she will be monitored to see how well these cells continue to produce ADA. A total of 10 children will be included in this protocol, the most extensively and critically reviewed clinical study ever undertaken. We should know in a few months if it is working, but there is little doubt that it will. It is not often you can talk about a new era in medicine, but this truly is one of the greatest steps forward in the history of humankind. If we can do it for SCID, we can do it for Lesch-Nyhan, Tay-Sachs, or any other genetic disorder for which we identify and clone the gene and provide correction before irreparable damage occurs. Many of the hundreds of genetic causes of MRDD where we have had nothing to offer before, will become amenable to treatment by this approach and the modifications of it that will surely come.

Fetal Therapy. Another new frontier is fetal therapy, first begun in the 1960s by Liley with intrauterine transfusion for Rh disease, and most recently crossed by Mike Harrison and Mickey Golbus with actual fetal surgery, in which the fetus is removed from the uterus, a congenital anomaly such as obstruction of the urinary tract or diaphragmatic hernia is corrected, and the fetus is returned to the uterus for the pregnancy to continue. These are heroic procedures, but there are other variants of fetal therapy that are coming that mean that we will at last have something to offer after fetal diagnosis other than genetic counseling and the option of pregnancy termination for fetal defect. At the recent Congress of the Transplantation Society, physicians from France reported success in treating fetuses with immune deficiency or thalassemia by injecting liver cells from aborted fetuses into the fetuses with the genetic defects. Although these studies will have

to be replicated and confirmed, it is likely that this will be an effective means of fetal therapy for some genetic disorders. Another approach to fetal therapy is still in the animal study phase, and involves prenatal surgery to correct neural tube defects such as spina bifida or meningomyelocele to prevent paralysis. Neurologist John Freeman and neurosurgeon Dan Hafez postulated that the permanent neurologic damage from this lesion might be due to exposure of the bare spinal cord and nerves to toxic substances in amniotic fluid, and if the lesion were closed before the damage occurred, paralysis might be avoided. Working with a mouse model, Hafez has demonstrated that early closure of the meningomyelocele in the fetus eliminates postnatal neurologic impairment, while sham operated controls exhibit all the usual postnatal neurologic deficits. If this holds with other animals and carries over to humans, our screening of pregnancies with serum AFP and ultrasound for neural tube defects may result in the ability to correct the lesion prenatally and prevent neurologic complications.

Neurobiology. The 1990s have been declared the "Decade of the Brain" by Congress and Presidential proclamation, and neurobiology represents another exciting frontier for the MRDD field. Discoveries relating to the programmed development of the CNS, abnormalities in nerve cell migration that could account for some forms of MR, and discoveries that nerve cells can in fact regenerate in the brain and spinal cord, offer whole new fields for study and potential therapeutic application to MR, spinal cord injury, cerebral palsy, and learning disabilities. This is one of the hottest and most exciting areas in all of medicine and biology, and once again you in the MRDD field are right in the middle of it.

Treatment Effectiveness. Another area of great importance in the MRDD field, even if not exactly a new frontier, is treatment-effectiveness research. Few other fields have so many varieties of treatment approaches, often bordering on fads, as MRDD. Perhaps it is because there are so many conditions where we have little to offer beyond diagnosis, that we have so many pet but unproven approaches, but for the sake of protecting patients and parents from exploitation, and thanks to PL 99-457 that provides Federal support for early identification and treatment of MRDD, to protect the Federal dollar, it is important that we study not only those treatment approaches that we suspect are not effective, but also those treatments that we believe are effective but have not been proven so. In addition to research of this type that will be supported by NICHD and the Department of Education, a whole new Federal agency in the Public Health Service, the Agency for Health Care Policy and Research, has been established by Congress to study the effectiveness of treatments. We badly need studies of this type so that money will not be spent on useless treatments, and parents and patients will be spared the wasted time and effort of going through them.

New Hazards and Challenges. Just when we seem to make progress against one disorder, another often appears to take its place. We eliminated PKU only to create maternal PKU. We are eliminating H.flu meningitis, but it appears its case numbers will be more than made up for by patients with congenital AIDS. As if that were not enough, the national cocaine epidemic promises to flood the MRDD field with "crack babies" showing signs and symptoms of brain damage due to their mothers' use of cocaine during pregnancy. Finding ways to manage the irritability, learning problems, and antisocial behavior of these children will challenge a whole generation of MRDD personnel. Add to that an increasing number of ever-smaller low birth weight babies who survive but with some neurologic impairment, an increasing number of babies born to unmarried teenage mothers and thus high-risk by definition, and rising rates of babies with congenital syphilis who are slipping through our screens, and you have an unending source of patients and topics for the MRDD research agenda as it addresses the new morbidity.

Resources. Somehow resources must be found to keep pace with the opportunities and growing challenges of this research agenda. Of great concern is the fact that every year the percentage of Federal funds spent on MRDD that are allocated for research continues to decrease. Growth in service and support programs is certainly needed and commendable, but it is essential that research keep pace with this growth. Otherwise, we will continue to have to invest in costly services for conditions that could have been prevented, or in treatments that research could have shown were ineffective or could have been improved. We must continue to develop new knowledge and evaluate treatment approaches. The NICHD is committed to support that endeavor so that research will coexist with and buttress service delivery across the entire country. Only in that way will patients and parents receive the full benefit of our efforts.

Preventive Strategies

So far I have focused primarily on research and what it has provided in new knowledge for preventing and treating MRDD, arguing that we must continue to try to learn what we do not know, and learn how to apply effectively what we do know. Let's turn now to the things we need to do and can do in our states and communities to put into effect what our scientific advances have made possible. This will really be what you will be talking about in the whole rest of this conference, so I can mention only what I consider most important.

High on the list of preventive strategies is immunization. We have the magic bullets that allow us to prevent the MRDD consequences of measles, rubella, and now H.influenza, but we are not using the gun to shoot them. We have had to pass laws to

try to force people to do what is good for their children, and require immunization for school entry. That works by age 5, when we achieve 95 percent immunization levels. But it is not working at younger ages when immunization is needed. Data from California, for example, indicate that statewide only 11 percent of children get all their vaccines at the right time, and only 50 percent are completely immunized by age 2. Some of the developing countries I recently visited in Africa do better than that. Rates of immunization in our inner cities are even worse, so much so that health authorities warn that we are on the verge of epidemic outbreaks there of measles, rubella, and even polio if the situation is not corrected. With the availability now of H.flu conjugate vaccine for infants, early immunization becomes even more important. We need your creative ideas and efforts on the home front to get H.flu conjugate vaccine quickly added to the required standard immunization regimen, and new methods developed to assure early immunization. For example, if we can compel evidence of immunization for school attendance at age 5, perhaps we should compel it in order to claim a dependent income tax deduction at age 1 and 2, or for AFDC welfare benefits to be received. Think about what you can do to realize the full benefit of this most effective of all preventive public health measures.

In considering all the conditions that negatively affect mothers and children, it is hard to imagine a more significant one than an unintended and unwanted pregnancy and birth. The data are clear to indicate that a wanted child is better cared for during pregnancy and after birth, has a lower risk of infant mortality, is healthier, and is more likely to receive the attention and stimulation that promote normal rather than deficient intellectual and social development. Yet here again our record of performance is not good. The latest National Survey of Family Growth indicates that in the U.S. 52 percent of 11 pregnancies and 80 percent of those among teenagers are unintended; half of these pregnancies end in abortion, but one fourth of all births are unintended either at the time or at all. Clearly, improved family planning services must be a component of a strategy for preventing conditions that negatively affect mothers and children and contribute to MRDD.

Preventing MRDD clearly begins before birth, and includes early comprehensive prenatal care. There are several points to emphasize here in your efforts. First, there has to be someone to provide prenatal care, and if we don't do something about our medical malpractice laws, there soon won't be. Family physicians are eliminating prenatal care and delivery from their practices at record rates, and OB/GYNs are becoming GYNs only due to exorbitant malpractice insurance premiums driven by huge awards in lawsuits claiming perinatal injury. Some states have initiated reforms to preserve medical care for pregnant women; you need to press this in every state. In addition to the caregiver, there must be a care seeker and receiver. Unfortunately,

prenatal care is often sought too late or not at all, and our national performance is getting worse, not better. We need your ideas and help in achieving our health goal for the nation of getting more pregnant women into regular prenatal care, beginning in the first trimester.

We don't know everything about prenatal care that improves pregnancy outcome, but some things we know for sure. We know that cigarette smoking in pregnancy clearly increases the likelihood that a baby will be born prematurely or have low birth weight (LBW), will die in infancy, will die of Sudden Infant Death Syndrome (SIDS), or will function at a lower intellectual level. We know that of all the things we can do, the most effective intervention to reduce the incidence of LBW and to improve pregnancy outcome is for a woman to stop smoking during pregnancy. Similarly, it is important for her to minimize alcohol intake and avoid drug abuse, especially of cocaine. Your efforts to achieve this in prenatal care programs in your states will contribute to reducing MRDD resulting from these activities in pregnancy.

There are a whole host of activities to be undertaken after birth to prevent MRDD, but I will single out just two for special emphasis. The first is injury prevention, especially head injury, the leading cause of death and disability in childhood. We have the beginnings of effective interventions--infant car seats, seat belts, bicycle helmets, etc.--and it is our job to encourage their use, by law or by any other effective means. The second strategy for preventing MRDD that has extremely broad implications is early intervention with developmental stimulation for high risk infants and children, building on the Head Start model. President Bush has made good on his commitment to Head Start, proposing a major funding increase for the program that was enacted by the Congress this fiscal year, and proposing another major funding increase for it in the FY '92 budget he submitted February 4. These expansions will bring the proven benefits of Head Start to many, many more children. What research such as the Infant Health and Development Program (IHDP) has shown is that high-risk children benefit greatly from a program like this begun in infancy, and that for high-risk populations, interventions may need to be applied then rather than waiting until age 3 or 4 if maximum benefit is to be obtained. The results of the IHDP study are so dramatic and clearcut that, as you plan your prevention programs at the state and community level, implementing an effective early intervention program for high-risk infants needs priority consideration.

We have covered a wide range of topics, beginning with early government efforts on behalf of persons with MRDD, going on to consideration of advances from research, and ending with a menu of selections for preventive activities to be undertaken to address conditions that negatively impact mothers and children. I hope it has provided an introduction and overview that will whet your appetite for the offerings to come in the

rest of this conference, and that you will return home committed both to supporting the research that is essential for developing new knowledge, and to implementing new and innovative programs that will apply the knowledge we have in ways that will be most effective in preventing MRDD, and in serving and improving the lives of persons with MRDD everywhere.

Awards Luncheon Address

Speaker: Louis W. Sullivan, M.D.
Secretary
U.S. Department of Health and Human Services

Award Recipients:	**Felix de la Cruz, M.D.**
	Ruth Winstead Diggs, Ed. D.
	Florida Developmental Disabilities Council
	Henry C. Meece, Jr., Ph. D.
	George Tarjan, M.D.
***Award accepted by:**	**K. Joseph Krieger, Executive Director**

COMMENTS ON THE NATIONAL EFFORT TO PREVENT MENTAL RETARDATION AND RELATED DISABILITIES

by Louis W. Sullivan, M.D.
Secretary
U.S. Department of Health and Human Services
Washington, D.C.

Thank you very much for that warm welcome, Dr. Anderson, and thank you, ladies and gentlemen. I can think of no finer way to commemorate the Silver Anniversary of the President's Committee on Mental Retardation than with this Summit.

I want to begin by taking special note of a very important event that shows we are making progress. Last July, President Bush signed into law the Americans with Disabilities Act. This was an historic event because it confirmed anew the nation's resolve that all people with disabilities have a valued place in our society.

But our concern is not limited to helping those with disabilities. Our mission is broader than that. We are here today to consider ways to prevent disabilities.

I want to speak with you for a very few minutes on the theme for this summit: "Preventing the 'New Morbidity' -- Improving Options for Mothers and Children." President Bush and I are committed to that. In our health goals for the nation for the Year 2000, my department called for reducing the prevalence of serious mental retardation in school-age children to no more than 2 per 1,000 children, from 2.7 per 1,000 children.

There are many ways to improve the options for mothers and children. These include research, immunization, improved access to programs, and the practice of personal responsibility for a healthy life.

First, research: As a clinical researcher, I know the importance of research. So does President Bush. Our President has proclaimed the 1990s as the "Decade of the Brain." We are expanding our commitment to research on the mind and the brain. Our research programs are wide-ranging. They include work at the molecular level, intervention programs targeted at high-risk infants, and the use of computer assisted devices to help those with mental retardation learn to read.

A second way to improve options and prevent the new morbidity is with immunization. As you know, we recently licensed the first vaccine effective in infants against meningitis associated with Hemophilus influenza type b, the leading cause of acquired mental retardation in the United States.

There is a third way to increase options for mothers and children. We can prevent mental retardation in a vast number of cases if we can reach pregnant mothers and infants with medical care, nutrition, and the personal counseling that they desperately need in prenatal and neonatal stages.

Let me say a word about improving access to programs. We are helping the states to adopt one-stop shopping initiatives that will make available, under one roof, the various health and social services that are targeted to pregnant mothers and infants. And we have expanded Medicaid eligibility for pregnant women and infants to 133 percent of the poverty line. In addition, the President's proposed budget for next year projects that Medicaid outlays alone will be $3.8 billion for 2.4 million women and infants, an increase of $300 million over the previous fiscal year.

You and I know that research, immunization, and access to care are vital. But so is a sense of personal responsibility for good health, the fourth way to improve options and prevent illness. This is an appropriate time to say a special word of praise for our Assistant Secretary for Human Development Services Mary Gall; Assistant Secretary for Health Dr. James Mason, and Surgeon General Dr. Antonia Novello, who are helping me carry the message of personal responsibility for good health, and healthy babies.

We are calling for a new "culture of character" that nurtures values such as self-discipline and mutual concern for the health and well-being of our friends, families, and neighbors. Each of us must heed the message to stop smoking; end drug and alcohol abuse; avoid the high-risk behavior that spreads the AIDS virus; seek early prenatal care; improve eating habits; increase regular exercise; wear seatbelts and take other necessary safety precautions; and get the necessary medical examinations and vaccinations.

This message applies with special force to women of childbearing age, and to the men in their lives. Some 900,000 infants are born each year to women who smoke. Far too many are born prematurely or with low birth weight, and thus suffer mental and physical disabilities. We are just beginning to reap the grim harvest of physical and mental disabilities resulting from maternal drug and alcohol abuse. I have seen these fragile victims of maternal drug abuse struggle for each breath in the pediatric intensive care units I have visited. As a physician and as a father, it is a sight to which I cannot

become accustomed. Our national drug control strategy has made prevention and treatment for pregnant women and their infants a top priority.

But, what is needed more than anything else is a new attitude about the value of life and health, an attitude that is reinforced at every turn by public officials, health care professionals, the media, churches, schools, and by each of us here today. I know you understand that. And that is why I have every confidence that this will be a successful and productive summit.

Thank you all for your efforts, and your service.

Summit Panel I

WHAT WE CAN AND MUST DO

February 6, 1991

MODERATOR: Christopher DeGraw, M.D.
Coordinator
Children and School Programs
Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services
Washington, D.C.

PANELISTS: Godfrey Oakley, M.D.
Ashley A. Files
Allen Crocker, M.D.

IMPACT OF THE "NEW MORBIDITY" ON EPIDEMIOLOGICAL RATES IN MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

by Godfrey Oakley, M.D.
Chief

Centers for Disease Control
Atlanta, Georgia

Epidemiology plays a unique and fundamental role in the prevention of mental retardation. Today I will focus on the epidemiology needed to increase our ability to prevent birth defects, developmental disabilities, and other disabilities with an onset in childhood. The "New Morbidity" is a term the President's Committee on Mental Retardation used to mean childhood disability (especially mental retardation) that is associated with poverty.

Surveillance, etiologic research, and prevention effectiveness research are components of prevention epidemiology. I will give examples of these components as they relate to the new morbidity. The main conclusion is that serious gaps exist in prevention epidemiology and that these gaps could be best filled by developing a network of prevention epidemiology centers.

I am pleased to join you in celebrating the 25th anniversary of the President's Committee on Mental Retardation (PCMR) and to speak on the epidemiology of the new morbidity. This conference continues a long tradition of PCMR-sponsored discussions on important prevention issues. The Centers for Disease Control (CDC) Disabilities Prevention Program is now building on foundations that PCMR catalyzed. The 1977 International Summit on Prevention of Mental Retardation was a sentinel prevention conference. It was cosponsored by PCMR, the American Association on Mental Retardation, and the National Association for Retarded Citizens. Such notables as Hugo Moser, Bob Guthrie, and Elizabeth Boggs spoke to us of how mental retardation can be prevented. PCMR conferences contributed much to the prevention science base that was to fuel the many state-based developmental disabilities prevention plans that were developed in the 1970s and 1980s.

Our Disability Prevention Program now supports nine state prevention programs that are, in large part, modeled after these early programs. This year we plan to at least double the number of state-based prevention programs receiving CDC support. You can

expect to see a "request for proposals" to be announced sometime in April or May. I would like to acknowledge the leadership of the National Council on Disability in making this new program a reality at CDC.

CDC, for the first time, now has a director who is a pediatrician. Dr. William Roper is committed to making child health a major CDC priority. Our goals in child health center around the prevention of infant mortality and the prevention of childhood disability.

CDC and the National Council on Disability are in the early stages of developing a national prevention agenda. This agenda will build on the Institute of Medicine's Disability in America which will be unveiled in mid-March. We are now working with a group of about 30 experts to write a working paper on the prevention of disabilities that have their onset in childhood. A prominent topic of their deliberations is prevention of the New Morbidity. The working paper will be discussed at the National Conference on Disability Prevention that will be held in Atlanta, June 5th through the 8th. You are all invited.

Although the working papers and the national conference deal with the prevention of disabilities from all causes and in all age groups, much work will specifically address the prevention of birth defects, developmental disabilities, and other disabilities with an onset in childhood. This prevention plan will include plans for both primary prevention and the prevention of secondary conditions in persons with primary disability. The prevention agenda includes access to care, access to prevention services, basic/molecular research, and surveillance and epidemiologic research. Our planning activities focus on improving access to care and preventive services and improving surveillance and epidemiologic research. This morning I will limit my remarks to surveillance and epidemiology as I discuss the new morbidity.

Prevention epidemiology, as I use the term, is a process by which the prevention science base is designed to direct program implementation and public policy. Our goal is to establish a science base that can convincingly show what components of the new morbidity are preventable.

Today I will concentrate on the following four questions:

1. What observable outcomes can serve as measures of the new morbidity?
2. What are the major epidemiologic components of the prevention science base for the new morbidity?

3. Where in Federal and state agencies, universities, and other settings can prevention epidemiology be done?
4. Who should provide the advocacy for prevention epidemiology?

What observable outcomes serve as measures of the new morbidity?

We use the term "new morbidity" as it was defined by Dr. Al Baumeister and colleagues in their 1988 monograph, which was sponsored by the National Coalition for the Prevention of Mental Retardation and published by PCMR. Their definition is provided in the title of the monograph: "Preventing the New Morbidity: A guide for State Planning for the Prevention of Mental Retardation and Related Disabilities Associated with Socioeconomic Conditions."

Mental retardation is a major component of the new morbidity, especially mid mental retardation defined by IQ levels in the 50-to-70 range. Additional outcomes such as mental retardation with an IQ level less than 50, attention deficiency/hyperactivity and other mental disorders are also associated with socioeconomic disadvantage. And finally, activity limitations as reported in the National Health Interview Survey are more concentrated in this group. There are Year 2000 Objectives for serious mental retardation (IQ <50) and mental disorders, including attention deficit and hyperactivity, and activity limitations. We believe it is a most important epidemiologic challenge to develop valid measures for all those outcomes, especially mild mental retardation. CDC's Dr. Marshalyn Yeargin-Allsopp and colleagues have developed ways to use special education and other data from metropolitan Atlanta public schools to measure the prevalence of developmental disabilities. They will begin publishing their results this year. Measuring the prevalence of disability is but one feature of prevention epidemiology. This point leads us to the second question.

What are the major epidemiologic components of the prevention science base for the New Morbidity?

The major epidemiologic components of prevention science base include:

a. A scorecard for monitoring to provide direction for prevention programs and public policy;
b. Etiologic research to discover underlying causes and risk factors that provide leads for future preventive interventions, and;

c. Prevention effectiveness evaluation to ensure that preventive interventions are truly effective.

First, let's consider the "scorecard". We need a reliable scorecard to monitor our progress in achieving the Year 2000 Objective for preventing childhood disabilities.

In the early 1970s, PCMR established the goal of reducing the prevalence of mental retardation from biomedical causes by 50 percent. This goal was laudable, but we had no way to track our progress. Surely, important progress has been made by the many interventions directed at the prevention of congenital rubella, phenylketonuria, and other metabolic diseases, kernicterus due to Rh hemolytic disease, and lead poisoning and other environmental teratogenesis.

Our failure to document this progress may contribute to the general perception that childhood disabilities cannot be prevented. We must correct this misperception. Childhood disabilities, including much of the new morbidity, can be prevented. A better scorecard will help get this important message out. Better surveillance is needed to promptly recognize increasing prevalence trends over time for developmental disabilities. During the 1950s, at Minimata Bay, Japan, mercury environmental contamination caused on increase in the rate of cerebral palsy from less than five per 1,000 births to more than 70 per 1,000 births before the epidemic was recognized. Today, how effective would United States surveillance be to detect a similar epidemic? Investigative reporters, including Mr. Eugene Smith, who took this famous photograph, were more instrumental in resolving this crisis than their counterparts in the health sector.

Those of us concerned with the prevention of childhood disability have much to learn from the infant mortality scorecard. We all know that infant mortality in this country is about 10 per 1,000 live births and that this rate has dropped precipitously in the last 50 years. We also know that the United States infant mortality rate is not as good as the rate in many other countries. In contrast, I suspect that few of us have a similar understanding of how we stand in the area of childhood disability. We shouldn't excuse ourselves just because disability is more complicated to measure than mortality. Remember, there are complicated aspects of infant mortality. There is neonatal mortality, postneonatal mortality, perinatal mortality, stillbirth, spontaneous abortion, and early fetal loss. Despite this complexity, we have good agreement of what is what among health professionals and even public awareness of our summary measures. We need to develop similar measures for childhood disability so that the public realizes the extent of the morbidity problem, and the number of children with disabling conditions. It can be as simple as one-two-three. One percent of all children born, die in the first year; two

percent will have developmental disabilities; and three percent have major birth defects. By the time a birth cohort reaches adolescence, six percent will have activity limitations -- that is chronic health conditions that limit school activities. Twelve percent will have mental disorders -- a categorization that includes attention deficiency/hyperactivity, depression, and drug addiction.

Obviously, there is some overlap between categories. The new morbidity is an important contributor to all of these areas. We invite you to work with us as we develop measures of these outcomes and establish the scorecard.

Of course, just agreeing on indices of childhood disabilities is not enough. The data must be collected and analyzed appropriately. But we will address these issues after discussing the other two major epidemiologic components of the prevention science base.

A second epidemiologic feature of the science base is **Etiologic research.** Etiologic research is the study of underlying causes of, and risk factors for, disability. Discovery of previously unknown causes can provide the basis for developing future preventive interventions. Understanding the magnitude of risks provides valuable guidance for clinical management, for priority setting of prevention programs, and for the formulation of public policy.

Knowing the causes and risk factors provides the basis for developing preventive interventions. I will illustrate this point with Fetal Alcohol Syndrome (FAS), an important component of the new morbidity. We distinguish two separate sets of causes and risk factors. The first set of risks concerns the development of FAS in the infant. The second set of risks influences the development of a disability in children born with FAS. Maternal alcohol abuse is a risk factor for the development of FAS. Only through etiologic research will additional risk factors be identified. For example, we are interested in developing laboratory technology that can identify women with genetic susceptibility to alcohol teratogenesis. Such technology could provide the basis for new interventions to prevent the initial development of FAS.

The second set of risks influences the development of disability (or functional limitation) in persons who have potentially disabling conditions. We cannot assume that the disability status of children born with FAS is determined at birth only. We must use etiologic research to search for postnatal risk factors. Some disability prevention programs for persons with FAS can be based on the prevention of these postnatal risk factors. We need to study how postnatal factors (such as intellectual stimulation, iron deficiency, or blood lead levels) influence the risk of disabilities such as mental retardation, attention deficit, or severe conduct disorders.

Epidemiologic study can quantitate the disability risks for persons with potentially disabling conditions. We need to know of children with FAS: What is their risk of having an IQ of less than 50? What is their risk of having an IQ of 50 to 70? What is their risk of having attention deficit or a severe conduct disorder? We have begun to fill in some of these risks, but much remains to be done.

A final epidemiologic component of the prevention science base is **prevention effectiveness research.** Child health is impaired in this country everyday because we have not been able to do the high quality research that is needed for excellent policy decisions. We know whether middle-age men should take an aspirin a day to reduce mortality from heart attacks. We do not know what needs to be done to prevent prenatal and a variety of other diseases that contribute to the new morbidity and help our children.

We need rigorous evaluation before interventions are widely implemented. Let me give you an example of FAS. Dr. Ken Jones has been an ardent supporter for the prevention of FAS. He discussed possible interventions for preventing FAS at the 1977 PCMR Summit. Today, almost 15 years later, many of these interventions are being implemented, but we can still only speculate about their efficacy.

There are bright spots in our prevention effectiveness research. The expensive and properly controlled polio vaccine trial sponsored by the March of Dimes is a historical landmark. It provided unequivocal data that the vaccine would prevent polio and was followed immediately by a public policy to immunize all children. One measure of that success is that as a middle-age American pediatrician, I have never seen an acute case of polio. The recent Robert Wood Johnson Foundation, NICHD- and MCH-supported multi-center study of an early intervention program for low-birth weight infants was also appropriately rigorous. I hope that we take the public policy action needed to use these effective interventions to prevent much of the mental retardation part of the new morbidity. CDC and World Health Organization collaborators in China are conducting a randomized trial to detect whether or not multivitamins in the periconceptional period prevent spina bifida. We shall determine whether or not a simple multivitamin pill is the wonder drug to prevent spina bifida and anencephaly. Around the world 400,000 infants are born with these major disability conditions. It is our dream that the vitamins will be shown to be effective and that we shall be able, around the world, to prevent spina bifida the way we prevent rickets and hypothyroidism. That is, we will be able to fortify the food chain. More such studies are needed for our more promising prevention leads.

More prevention-effectiveness research is also needed to test interventions to prevent disabilities in children with special health care needs. The systematic,

randomized treatment protocols for childhood cancer provide an excellent model. This research has dramatically increased survival. For example, in leukemia trials 20 years ago, the disease was uniformly fatal. Ninety percent of these children died within 4 years. If pediatricians had not had the courage to realize that RCTs were needed, it is unlikely that we would be doing so well with learning. Today, more than 70 percent of all children with leukemia can be cured. We believe that randomized treatment programs for other low-incidence disorders can bring similar improvements. Maternal diabetes and birth defect prevention are areas needing attention.

Prevention epidemiology, as we define it, is the maintenance of a scorecard to monitor the progress of prevention efforts, etiologic research to identify leads for future interventions, and prevention effectiveness research to ensure that proposed interventions are truly effective. Three special needs of prevention epidemiology warrant discussion before I move on.

First, because the clinical disorders responsible for childhood disabilities occur, for the most part, at a low incidence, complete epidemiologic competence must include access to relatively large sample sizes. In other words, many important questions cannot be answered by analysis of data collected by current Federal sponsored surveys using national representative, but small samples. Second, to quantitate the risk of disability associated with clinical diseases/disorders and to do the prevention effectiveness research to evaluate interventions, longitudinal studies of three or more years are required. And finally, more discussion among experts is needed to develop common approaches to be used for scorecard purposes. We need to agree what surveillance data should be collected and how it should be analyzed.

I will now shift to the third question. **Where in Federal and State agencies, universities, and other settings can prevention epidemiology be done?** I suspect that there are representatives here at the Summit from most, if not all, groups involved in the epidemiology of the new morbidity. Much of the support for this epidemiology comes from the Federal sector. The National Institutes of Health, the Division of Maternal and Child Health, the Mental Health and Alcohol Institutes, the CDC, and the Department of Education provide major support for research that contributes to the prevention science base. A few states provide major support in this area. A notable example is the California Birth Defects Monitoring Program. In addition, the importance of foundation support cannot be overstated. Some foundations do not have annual funding cycles that can limit the public sector in committing support for long-term prevention-effectiveness research. The major contribution of the Robert Wood Johnson Foundation to study of early intervention, which I mentioned earlier, is a dramatic example in this area.

Epidemiologic research is conducted in a variety of settings. Some Federal and state agencies have intramural research programs. Epidemiologic research is also done in academic settings, such as schools of public health, University Affiliated Programs, and medical schools. And finally, research in this area is probably done in industry, but the findings are not well disseminated.

Although much of today's research has important applications in prevention epidemiology, it is often initiated for other purposes -- the implementation of prevention programs is not always a primary goal. Findings are often not reported in terms that are meaningful to persons who design and implement prevention programs.

Therefore, we believe that a network of prevention epidemiology centers -- a structured federally-supported program in which epidemiologic researchers can address scientific issues of importance to state and community prevention programs. This group would do the following:

a. Develop common approaches to data collection and analysis that permit the monitoring of regional and temporal trends in the prevalence of critical childhood disabilities.

b. Advise and consult with state- and community-based programs in the interpretation of the current science base.

c. Develop epidemiologic methods for use by state- and community-based prevention programs in improving efficacy and accountability.

d. Conduct etiologic and prevention-effective research that have national significance.

e. Provide epidemiologic training for personnel in state prevention programs.

The network of prevention epidemiologic centers must establish programs with the critical mass to serve as a regional and national resource. We should start with existing programs that have already developed a critical mass of epidemiologic expertise and add others as resources permit. Additional Federal funding should supplement the primary support obtained from other sources. Participants in the network should also

have access to rich data bases that could be used to address important questions in prevention epidemiology. This recommendation brings me to the last question.

Who should provide the advocacy for prevention epidemiology?

Securing resources to support prevention epidemiology is especially challenging today as control of public spending has become a high priority in and of itself.

In these times, we need more than ever to set priorities for prevention programs on the best science available. Leadership is needed in our field to inform decision makers of the importance of childhood disabilities prevention and of the essential role that prevention epidemiology can play in ensuring efficacy. In summary, prevention epidemiology is the scorecard that helps us monitor our progress in prevention; etiologic research to develop leads for new, more efficacious interventions; and prevention effectiveness research to allow us to ensure that proposed interventions are truly effective before they are widely implemented.

Who, specifically, should provide the advocacy for prevention epidemiology? Of course, the leadership for this advocacy must come from those of us attending this Summit. I am counting on your support.

HEALTHY PEOPLE 2000 OBJECTIVES FOR THE NATION--IMPACT ON PERSONS WITH MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

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In *The Republic*, Plato writes of Socrates' debate with a group of Athenians concerning the nature of the Ideal State. To make his point, Socrates begins by describing how people in his vision of the Ideal state will live:

> [They] will feed on barley-meal and flour of wheat, making noble cakes and loaves... For dessert we shall give them figs, and peas, and beans; and they will roast myrtle-berries and acorns at the fire, drinking in moderation. And with such a diet they may be expected to live in peace and health to a good old age, and bequeath a similar life to their children after them.

Frankly... Socrates' debating partners were appalled at this description, asking Socrates whether he expected people to live likes pigs. They insisted that people needed the comforts of life, to be given sweets, and meat of various kinds, perfume, and courtesans, and entertainment. Socrates gave in to their demands for a more comfortable and extravagant lifestyle, but he asked then: "and living this way, we shall have much greater need of physicians?" His fellows responded, "much greater."

As you can see, nearly everything we have proven by spending millions of dollars on research into nutrition, living moderately, and health promotion, Socrates tried to teach us hundreds of years ago!

In my remarks today, I would like to focus on a few aspects of the United States' efforts to, in effect, bring about a return to "Socratic living," concentrating on our use of national health objectives, as laid out in *Healthy People 2000: National Health Promotion and Disease Prevention Objectives.*

The first aspect of *Healthy People 2000* that merits particular attention is its usefulness as a planning tool, especially its use as a tool for building consensus and pulling together the many sectors and individuals who are necessary for achieving real health improvements at the local level. The second important aspect is the objectives' major focus on eliminating health disparities among subgroups of our population. In closing, I will relate each of these aspects to reducing the "New Morbidity."

***Healthy People 2000*: Building a Consensus**

Democracy and consensus building are messy and time consuming. When you ask Americans for an opinion, they give you one. *Healthy People 2000* took three solid years to prepare. It took that long because it is a national, not Federal, health policy statement. If we were to call it "national," we felt duty bound to ask the nation what it wanted to see in the objectives. A quick review of how we did that is instructive:

- We held seven regional hearings (about 300 people attended each one) and took written and oral testimony.

- We went to the annual meetings of 18 national organizations with an interest in the objectives and took their testimony as well.

- From these hearings, our partner, the Institute of Medicine of the National Academy of Sciences, took in 760 separate pieces of testimony.

- Twenty one, mostly Federal, working groups of approximately 30 members each were formed to write the first draft. These working groups used the public hearing testimony as the basis for their drafts.

- The Public Review version, published in September 1989, was sent to 13,000 individuals and groups; 700 sent in written comments on the draft. Nearly a year was spent sorting out these comments and resolving conflicting suggestions.

The Year 2000 Consortium

One way we were able to pull so many groups and individuals into the process was through the Year 2000 Consortium. Begun in 1987, the Consortium is made up of representatives of all the State and Territorial health departments and nearly 300 national membership organizations. Members of the Consortium joined simply because

they had an interest in the health objectives. As a result, members include such services organizations as the Girl Scouts and United Way, trade groups like the Grocery Manufacturers Association and health organizations such as the American Public Health Association and the American Medical Association. Groups self-selected into the Consortium because they could see the relevance of the objectives to their organization.

The Consortium has served many functions. Members of the Consortium publicized the objectives, nominated experts to review and comment upon the first draft of the objectives, and gave extensive comment on the Public Review draft. Perhaps most importantly, the Consortium helped the Public Health Service make some of our toughest and most controversial decisions. For example, the Public Review version contained an overarching goal of increasing life expectancy. Negative comment from the public, and from the Consortium members in particular, caused us to replace that goal with one to increase the span of healthy life. The thrust of the public comment was that it is cruel to simply extend life; for a national goal, we needed to concentrate on expanding the number of years everyone lives in good health. Although this line of public comment makes sense, it would have been difficult politically for the Public Health Service to abandon the life expectancy goal without public support. Another example is the case of the Environmental Health chapter of *Healthy People 2000*. Perhaps the most heavily criticized chapter in the Public Review version, the Environmental Health chapter, was completely rewritten for the final document. We needed the press of public comment, again, especially from Consortium members, to be able to justify taking a strong stand on environmental health issues. Through the Consortium, we had clear and credible public support for creating an activist set of environmental health objectives.

Achieving Consensus

As I mentioned earlier, when you ask thousands of Americans for an opinion, they give it to you. This fact alone can make consensus very difficult to achieve. But other aspects of the health objectives also made consensus a challenge. First of all, the objectives are very specific. Each objective is stated in terms of an absolute change: in ten years time, the nation will go from point A to point B. No objectives are stated in terms of such unmeasurables as "more" or "better" or "improved." Thus, consensus must be achieved on a specific target as well as a topic, and this can be a difficult task.

Second, the objectives guide resource allocation. Of course, whenever money is involved, we have a fight on our hands. A bit of emphasis here might be helpful. The objectives guide resource allocation, but they do not control allocation. Nonetheless, the influence on how public and even private funds are spent makes the objectives important to a wide range of groups and individuals; and as the objectives become more important

they also become more contentious. Ironically, by taking the public comments seriously and working to achieve consensus, we increase the difficulty of our job, because simultaneously, we increase the credibility of the document and expand the influence it can have nationally.

An Emphasis on Reducing Disparities

Now that I have, hopefully, made the case for using collaboration and consensus in making health policy, I would like to switch to an important, and relevant to this conference, aspect of the national health objectives. It would be difficult for me to overstate the importance of *Healthy People 2000's* focus on reducing health disparities among Americans.

Healthy People 2000 contains three broad, overarching goals. These goals are:

- To increase the span of healthy life among Americans;
- To reduce health disparities among Americans; and
- To achieve access to preventative services for all Americans.

Each of these goals is supported by the 300 specific objectives contained in *Healthy People 2000*, but probably none is so well supported as the disparity goal. In addition to the 300 objectives, *Healthy People 2000* includes just over 300 "special population targets." These targets were made part of the objectives whenever an identifiable gap between the total population and a particular subgroup could be identified. For example, there are about 60 special population targets for blacks (in such areas as coronary heart disease and infant mortality), 30 for Hispanics (in such areas as diabetes and health services receipt), and 25 for people with low incomes (in such areas as high quality preschool and lead poisoning). These targets highlight the necessity of targeting programs to people in the greatest need. Further, as progress toward the objectives is tracked over the decade, the special population targets will keep the issue of disparity before the Secretary of Health and Human Services, the Assistant Secretary for Health, our PHS Agency Heads, Congress, and advocacy groups. Taken together, the goals of *Healthy People 2000* assert that it is not sufficient to improve the "average health" of Americans. Real progress must be measured by assessing the health status of all groups within society and leaving no group out of that progress.

Tieing It All Together

My earlier points about the process we used to set the objectives, the overarching goal of reducing disparities, and the specific focus, objective by objective, on reducing disparities are particularly relevant for reducing the "New Morbidity." First, the New Morbidity is not entirely a health care/treatment problem. Socioeconomic variables play an important, if not determining, role. As a result, you will need to broaden you scope of partners beyond those who provide and study health care. Second, as you come together to form plans of attack on the New Morbidity, there will be countless disagreements in how your goals should be accomplished. The methods we used with *Healthy People 2000* to address precisely these issues, could be invaluable in achieving consensus in State planning.

In closing, I can only encourage you to make use of the strong points of *Healthy People 2000*. Reach out to all those groups and organizations that affect health, but that are often excluded from health planning and health solutions. Invite employers, school administrators and teachers, social workers, mayors, and recreation groups to play an active part. This is simple advise. I merely suggest that you avoid just talking to yourselves.

And last, focus in on making things better for the worst off. Do this because you will probably get much more bang for your buck. But also, do this because our friends Plato and Socrates would have put justice very near the top of their list of items to be included in the Ideal State.

A NATIONAL PREVENTION AGENDA INCLUDING THE INSTITUTE OF MEDICINE (IOM) STUDY

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When I heard about two years ago that a scholarly effort was going to be made on the topic of a national agenda for the prevention of disability, I was most excited. There is something provocative about the formulation of policy, particularly national policy. Though primarily a paper exercise, it calls on our juices to put it down like we really believe it and be prepared to stand behind it as the process plays out. It is a tantalizing exercise and one that is daunting, to say the least.

The assignment in this instance was a commission from the Centers for Disease Control (CDC) in conjunction with the wishes of the National Council on Disability (NCD) to the Institute of Medicine (IOM) of the National Academy of Sciences. This was a well-conceived transfer of assigned function. The Institute of Medicine is described as having the responsibility to make examination of policy matters pertaining to the health of the public and to serve in this fashion as an advisor to the Federal Government. The long history of endeavors from the Institute of Medicine in related topics gave it particular qualifications for undertaking the activity, including detailed studies on injury in America, on premature delivery, and on teenage pregnancy.

The product that was to emerge from this study gradually came to be called Toward a National Agenda for Prevention, and to use in its title the word "disability" in the largest and most generic sense. The chairperson of the staff activity at IOM was Andrew M. Pope and the chair of the committee itself was Alvin R. Tarlov. The mandate as presented by the CDC had five pieces to it. First was to gather some data on the public health significance of disability. The second was to review what major activities were underway in this territory. Third, to look at critical gaps in the knowledge. Four, to reflect a bit and decide how one could devise the materials that would offer a framework for setting priorities. Then lastly, and obviously the most expedient of them all, was to suggest a system by which in this country there could be a coordinated effort.

There were a number of things that were clearly not going to be done. There was not any attempt to be made in this particular venture to assess the cost of a

prevention program in all of its ramifications. The area of mental health was purposely and reluctantly left out of the disability considerations. The whole territory of ethical matters could be given only a partial consideration, and the bewildering elements generated by inequities in health insurance also could not be dealt with in any full way.

For the purpose, a committee of 23 members was assembled that derived primarily from university programs, several state agencies, one or two Federal agencies, various private facilities, hospitals, and a considerable consumer representation. They met over a period of two years in twelve two-day meetings, with extensive concurrent staff work. They formed working groups that were assigned individual chapters in the project.

It was determined early on that disability as it was envisaged by the National Council on Disability, the energizing force behind the project, would concern itself with four areas: developmental disability, injury, the effects of chronic disease and aging, and the entire area of secondary disability. The final executive summary and recommendations will be released in March 1991. The full report, rivaling that of *Healthy People 2000*, will be available in late May.

There are four features the product of the Institute of Medicine has granted to us that I think will be durable elements. First, they have produced an improved model for all to work with on what they are calling the disabling process. I will come back to that in just a minute because this is at the heart of a perception regarding where interventions can indeed be made.

Secondly, they have seen fit, substantially under the influence of the National Council on Disability, to give strong consideration to the whole issue of so-called secondary conditions. This means the elements that in the long run can influence greatly the outcome of a primary disability in terms of its progress and the meaning for that person's life. The fact that one of the four chapters concerned itself specifically with secondary conditions, I came to feel, is indeed very appropriate.

Thirdly, they have served as leaders in the improvement of vocabulary. They have insisted that the word disability be the predominant one. The word handicapped does not appear in this volume at all. They have further carefully monitored their syntax to use the phrase people or persons or individuals with disability rather than to invoke that noun as an adjective and thereby diminish personhood in the process.

The fourth element is this whole business of the clustering of the four pieces of the disability market, if you will: developmental disabilities, injuries, the effects of chronic

disease and aging, and lastly, the secondary conditions. Putting those four tracks together has been a challenging proposition and how successful they will be as bunkmates is hard to know. There are several places in the final recommendations where the language very carefully speaks of "balanced attention" to each of the four, and other places where it speaks of establishment of a "balanced program." I think for all of us who have stronger interests in one or another of those areas, there is a considerable mandate to see that this balance is indeed carefully maintained.

The first thing that one needs to deal with is the model of the disabling condition (Figure 1). This derives from Saad Nagi at Ohio State University, who in the middle 1960s felt that we needed to look at the genesis of disability with somewhat more dynamic considerations. He speaks first of the element of pathology, which is an interruption or interference in normal bodily processes that invariably leads in some degree to an impairment. The impairment as defined is a discrete loss or abnormality in function or structure. An impairment may or may not lead to a functional limitation. A functional limitation in this regard is an effect on performance or capacity of the person as a whole or of certain body systems. Such functional limitation may produce an impediment in performing socially-defined activities or roles. This would then constitute a disability, and implies reference to a specific cultural context.

He carefully points out, and the Institute of Medicine work underlines this with great certainty, that in point of fact there are risk factors that can intercede in controlling the flow of these matters. Also that there is an interaction to quality of life which gives a monitor across the process and is of considerable importance in the stakes that are at hand. The particular sensitivity is the fact that the perception for the functional limitation as truly a personal disability is a place where we as a people, as a culture, have an opportunity to make an intercession that is pertinent. It can render a tremendous influence on the ultimate outcome.

I will give you examples of how this model works. Suppose there is a direct injury to a person's arm in which the nerve supplying certain muscle groups is directly severed. That would be pathology. The impairment that would result therefrom would be an atrophy and weakness of the muscles dependent on that nerve. The functional limitation coming from it is that the individual cannot use the arm for certain mechanical tasks. The disability resulting would be that the person finds it necessary to change his job and that he can no longer swim recreationally, although now he can and does jog. Hence, there is a potential modification of the forward motion of the disabling process.

Another instance would be that a crush was received to the spinal cord that resulted in the impairment of a paraplegia. The individual in that regard has the

functional limitation of not being able to walk unaided or to drive a car without adjustment. This might produce the disability of the loss of his conventional employment and some of his social activities or it may not, depending again on how the scene has been set.

So therefore, if one is looking to the production of disability in our culture, there is indeed a moving component.

The equation becomes, in this regard, infinitely more complex, but more humanistic at the same time.

What was then the product? The product is 27 recommendations, divided into five categories. The full report itself will have nine chapters. Chapters Four, Five, Six, and Seven relate to developmental disabilities, injury, chronic disease and aging, and secondary conditions, respectively. Chapter Eight is a coordinating chapter, and Chapter Nine constitutes the recommendations. In each of the chapters there have been flagged in the text what are called needs. For example, in the developmental disabilities chapters, there are 15 needs identified from the data and the analysis that are presented. From those needs are formulated certain common concepts and then those are blended across the four disability territories to produce the 27 final recommendations (see Table 1). In that regard, these recommendations are very broad. In fact, they can be disarmingly non-specific, but they were to serve a series of conceptual purposes. They are capable of being translated into the details of individual programs, but as they appear in the final listing of recommendations, they are broad.

The exposition begins by saying that there must be someplace where a coordinated national effort in prevention occurs. They jump right in; they do not wait around. In recommendation number one, they suggest that the disability prevention program at CDC now become the National Disability Prevention Program, the NDPP. You will recall that the CDC was the commissioning organization for this study and it may have been a source of considerable embarrassment to them that the first recommendation advocated that they serve as the national leader. Those of us on the committee wrestled with this matter many times and the consensus was indeed that CDC has shown important leadership in the organizational and scientific base of prevention activities. Further, the CDC has a highly significant national beginning already in its Disability Prevention Program (DPP). It was endorsed that the DPP become the NDPP.

There was concurrently a suggestion that the private sector has much more that can be done (#2), and this involves universities, industry, and voluntary agencies as well. There should be a national advisory council appointed that will include both professionals

and consumers (#3), with representation from business, education, philanthropy, social services, research, and so forth. It will be appointed through the Secretary of Health and Human Services, will have an obligation to meet three times a year, and will be in many regards the watchdog of the entire system. The committee will have certain program assessment responsibilities as well.

Further, a Federal interagency council will be established comprising all of the components of the Federal Government that have major stakes in the disability and prevention area (#4). This includes, among others, the Maternal and Child Health Bureau, the National Institute of Disability and Rehabilitation Research (NIDRR), the Social Security Administration, the Alcohol, Drug Abuse and Mental Health Administration (ADAMHA), National Institutes of Health (NIH), Health Care Financing Administration (HCFA), CDC, and so forth.

Finally, there should be a critical assessment of progress periodically, with reports expected from both the National Advisory Council and the Federal Interagency Council that would review how it is going (#5). So there is to be by the perception of the Institute of Medicine report, a CDC-centered but broadly shared responsibility for looking at what our nation as a whole is doing in this area.

Again, echoing what Godfrey has described in the first session this morning, it is acknowledged that surveillance is an important component of it all, and that we need a conceptual framework and standard measures of disability (6, 7). It is suggested that the National Health Interview Survey be revised to be more effective in reflection of disability matters (#8), that we conduct comprehensive and longitudinal surveys (#9), and that a series of disability indices are developed (#10).

Recommendations 11 through 15 discuss a comprehensive research program with longitudinal research as a part of it again (#12). There is particular emphasis in research on socioeconomic and psychosocial disadvantage (#13). Expanding research on preventive and therapeutic interventions should be featured, in other words, how do they work (#14), and also upgrading of training for research in the area of prevention (#15). Again, this is compatible with resolves that are already native to the CDC.

Access to care was given considerable attention. This section is a somewhat bewildering one because it attempts to recapitulate many of the areas that MCH and other federal agencies and voluntary and professional organizations have long emphasized, such as comprehensive health services to mothers and children (#16), and long term care provision for children and other persons with disabilities (#17, 18). There is an intention to continue fruitful prevention programs (M20), to provide comprehensive

vocational services (#21), and to offer accessible family planning and prenatal services (#22). This group of recommendations encompasses an enormous area and will require substantial development.

Lastly, in the area of professional and public education, it has been suggested that professionals receive more preparation to develop a mindset that makes them appropriate workers in the prevention (#23,24,25), that there should be more attention to pubic education for potential personal roles (#26), and finally, that training opportunities be featured for family members and personal attendants.

This is a large serving. These 27 are a world. They are, I think, relatively incontrovertible. They are also quite a loving collection of ideas. Those of us with a special interest in the area of mental retardation and developmental disabilities can look at the book and say, "What is in it for us?" I have attempted to put together a collection of seven ideas of what, in my judgment are the principles that will bubble out and be most important for us.

First of all, the report appropriately endorses, the major contributions of the Centers for Disease Control, past, present, and continuing. Their capacity building programs in the states (now in nine and soon to be doubled) are a courageous and significant outreach to citizens and communities to become active in a systematic way. I believe they have been of seminal importance and will continue to be. So therefore, those of us with an identification with developmental disabilities have watched with considerable gratification as these activities have addressed concerns regarding developmental disabilities in those states.

Secondly, there will be a long-overdue Federal Interagency Council. I am sure Dr. Hutchins could tell us many stories about the dismay that thoughtful people have had regarding the incomplete capacity of Federal agencies to talk amongst themselves in a systematic and monitored way about their prevention plans. I remember when PCMR attempted, about five years ago, to make a list of Federal offices that had something important to do in the prevention of developmental disabilities, and the list ran to 35 or 40 agencies. They have never been able to get together effectively. This is at long last a start. We will watch with great interest as these folks put their cards on the table. There would be a national advisory committee with strong consumer representation parallel to it and a voice that will be well heard, would also be a significant gain. And lastly, be a requirement for monitoring and reporting the progress of the prevention activities on a national level which has never heretofore been suggested. It is my sincere hope that this will indeed be retained.

The need for improvement in the knowledge base is obvious; particularly in the most sensitive areas of the measurement of risks, the nature of courses, and the effectiveness of interventions.

It is gratifying that there has been in that next to last group of recommendations a proud public affirmation of the need for comprehensive services for mothers and children, for those at risk in general, and for the procurement of technology. The attention to quality of life considerations is welcome. These are all words that we use in our own meetings; and to have them presented here, in a form that can be widely circulated, and become part of the national conviction is of great value to me.

It is a valued emphasis, in the IOM report, there will be enhancement of related educational activities, particularly the training of families. It is good that there is endorsement of ongoing effective programs with no attempt to sidestep or minimize the quality of work already underway. And finally, I personally am very grateful that there has been, throughout all this work, a much more thoughtful model of the disabling process and an insistence upon a humanistic vocabulary.

In other words, if you ask if the Institute of Medicine report provided for us in mental retardation and developmental disabilities is a critically valuable tool, the answer is yes, and for the following reasons: we do believe in the CDC's importance; that national bodies should take some responsibility; that the knowledge base requires improvement; that comprehensive services are a cornerstone of a caring government; that educational activities are a necessary reinforcement of the whole business; and that it is appropriate that it be looked at from a consumer's point-of-view and with thoughtfulness in our vocabulary.

It remains to be seen whether there could have ever been anything analogous to the Institute of Medicine report that dealt only with developmental disabilities and their prevention.

I would suspect not in our times. This appears to be a period in our nation's history where we are getting together in broad efforts, producing large books and standing behind them. I think developmental disabilities would not have been able to have marshalled something as important. I would urge all of you here to regard very thoughtfully the Institute of Medicine report and look to it as a meaningful support of that in which we believe.

If those who administer the disability program nationally do not maintain what this report proclaims, namely "a balanced program, then loads of us will join together with torches and storm the barricades. Thank you.

REFERENCE

Pope, AM and Tarlov AR,eds: Disability in America; Toward A National Agenda For Prevention. Summary and Recommendations. Washington, D.C.: National Academy Press, 1991.

LIST OF RECOMMENDATIONS

ORGANIZATION AND COORDINATION

1. Develop leadership of the National Disability Prevention Program at CDC
2. Develop an enhanced role for the private sector
3. Establish a national advisory committee
4. Establish a federal interagency council
5. Critically access progress periodically

SURVEILLANCE

6. Develop a conceptual framework and standard measures of disability
7. Develop a national disability surveillance system
8. Revise the National Health Interview Survey
9. Conduct a comprehensive longitudinal survey of disability
10. Develop disability indexes

RESEARCH

11. Develop a comprehensive research program
12. Emphasize longitudinal research
13. Conduct research on socioeconomic and psychosocial disadvantage
14. Expand research on preventive and therapeutic interventions
15. Upgrade training for research on disability prevention

ACCESS TO CARE AND PREVENTIVE SERVICES

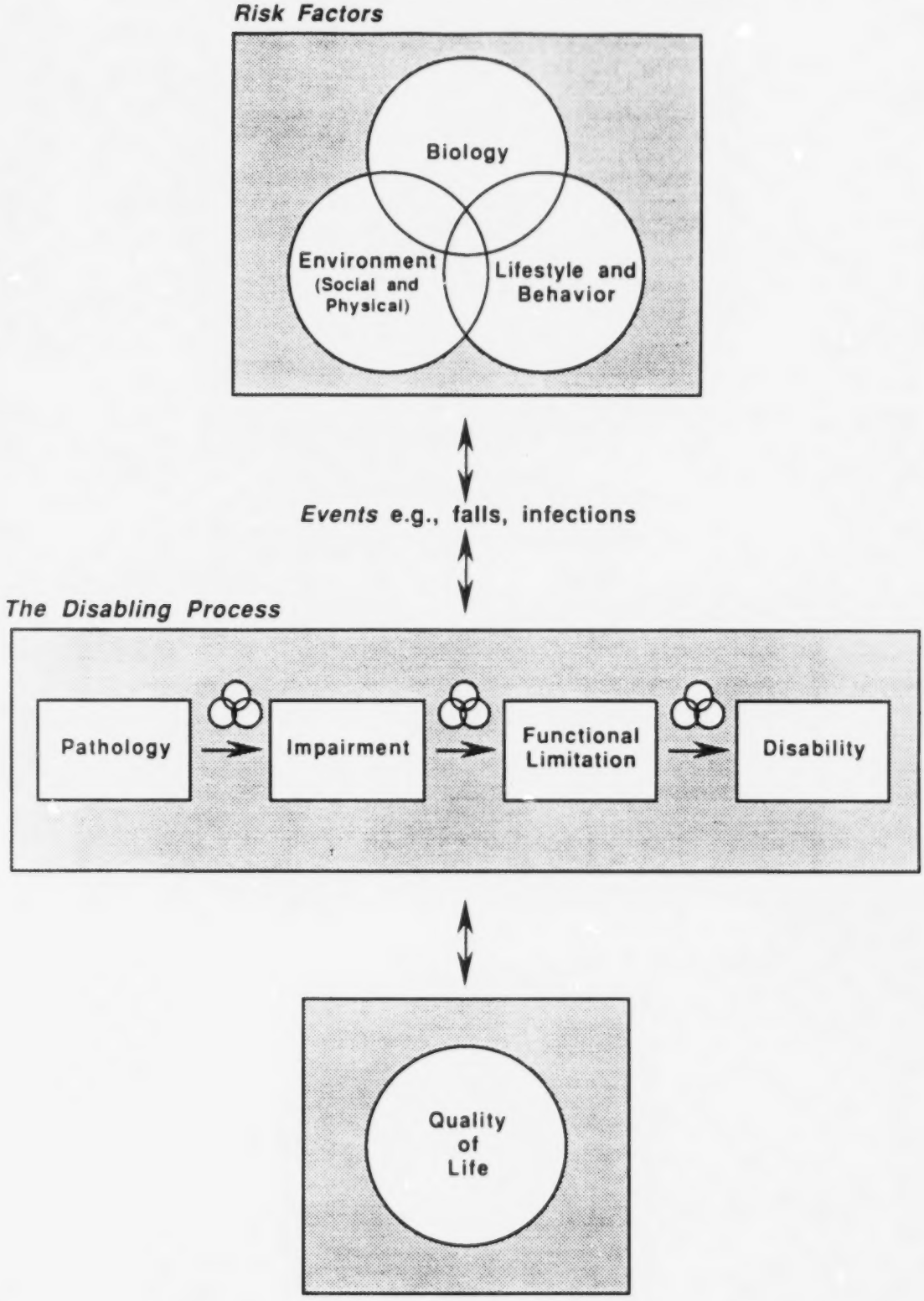
16. Provide comprehensive health services to all mothers and children
17. Develop new health service delivery strategies for persons with disabilities
18. Develop new health promotion models for persons with disability
19. Foster local capacity building and demonstration projects
20. Continue effective prevention programs
21. Provide comprehensive vocational services
22. Provide effective family planning and prenatal services

PROFESSIONAL AND PUBLIC EDUCATION

23. Upgrade medical education and training of physicians
24. Upgrade the training of allied professionals

25. Establish a program of grants for education and training
26. Provide more public education on the prevention of disability
27. Provide more training opportunities for family members and personal attendants of people with disabling conditions

Figure 1 (Crocker)
The Nagi model of the disabling process



Summit Panel II

PREVENTING THE "NEW MORBIDITY": IMPROVING OPTIONS FOR MOTHERS AND CHILDREN

February 6, 1991

MODERATOR: M. Doreen Croser
Executive Director
American Association on Mental Retardation
Washington, D.C.

PANELISTS: Alfred Baumeister, Ph.D.
Edward Zigler, Ph.D.

A MODEL FOR PREVENTING THE "NEW MORBIDITY": IMPLICATIONS FOR A NATIONAL PLAN OF ACTION

by Alfred Baumeister, Ph.D.
Director
John F. Kennedy Center for Research
on Education and Human Development
Peabody College, Vanderbilt University
Nashville, Tennessee

You received in your packet a copy of the draft "Guide to State Planning for the Prevention of Mental Retardation and Related Disabilities Associated with Socio-economic Conditions." My colleagues at Vanderbilt University, Mr. Frank Kupstas, Mrs. Luann Klindworth, and Dr. Pamela Zanthos, and I worked until the very remaining moments of the deadline before sending in the draft last week. In the few days since then we have undertaken a substantial revision, a few copies of which we have brought here. Pam Zanthos took the initiative to revise, correct errors of substance and wording, rewrite and reorganize the draft Guide. That which you find commendable about the document, I credit to Frank, Luann, and Pam. That with which you take issue, you can lay on this stubborn professor.

Over the past months, as we assembled information of all manner from various sources, we received continuing encouragement and advice from the Planning Committee. Many contributed time and thoughts to this effort. Two who worked with us throughout this entire process and whose specific suggestions are reflected in the draft Guide are Dr. Felix de la Cruz of the National Institute of Child Health and Human Development (NICHD) and Dr. Mike Adams of the Centers for Disease Control (CDC). We found ourselves increasingly dependent on the generosity and good will of these two distinguished individuals and scientists.

Members of the President's Committee on Mental Retardation (PCMR) have been consistently encouraging and helpful. These are not only very sincere and talented leaders, but I admire their courage in selecting me to develop the first version of this Guide. I can only hope their trust and faith is not misplaced. From the time we prepared the 1988 companion Guide to the very present, Dr. William Hummer, Chairperson of the Prevention Subcommittee, has been a major force behind PCMR prevention initiatives. Rarely do we have the good fortune to befriend a person of such genuine talent, dedication, and knowledge.

As Executive Director of the PCMR, Dr. Banik has revealed himself as both an outstanding administrator and professional. His level-headed and creative direction of the staff has been a source of stability and encouragement. In the midst of all this activity he injected a healthy dose of good humor at those very moments when my own despair seemed to be at its greatest. In addition to his other talents, he is a wonderful therapist and friend.

Notwithstanding vital contributions from all these highly-principled and talented individuals, planning for this summit meeting and the preparation of the Guide would not have been possible without Mrs. Laverdia Roach. She coordinated and spearheaded this effort with a sense of professionalism, dedication, purpose, and organizational ability that is awesome. As she dealt with the planning committee members, the PCMR, the various constituency groups, and the participants at this conference, I was impressed by her ability to keep us together on course. I watched her accommodate, adjust, and bring order to a seemingly endless variety of agendas, needs, and aspirations. If she decides after all these years to change jobs, my view is that she should be a career diplomat in the State Department.

Last summer, while staring from my bed at the ceiling of a hospital room, I received a copy of remarks that Secretary Sullivan made at the June meeting of the PCMR, when planning for this latest prevention initiative was formalized. He spoke in eloquent terms of the need for prevention, particularly within the context of the New Morbidity and attendant socio-economic considerations. In his foreword to the recently released Healthy People 2000 report, he stated that "Good health must be an equal opportunity, available to all Americans." That is a well-phrased encapsulation of the spirit underlying our mission.

Over the past few months, as the four of us tried to unravel the dynamics of health promotion for the purpose of drafting the Guide, I came to understand that Secretary Sullivan embodies so much of the hope and promise contained in our dedication to the cause of healthy children and families. His vision and leadership are essential in our pursuit of this cause.

THE NEW MORBIDITY MODEL

On this, the occasion of the 25th Anniversary of the creation of the President's Committee on Mental Retardation, it is truly fitting and appropriate that we again address the issue of prevention. For all its notable and varied accomplishments over this past quarter of a century, prevention of mental retardation has been perhaps the most consistent and visionary theme expressed by the PCMR.

As we know, two decades ago the PCMR established a national objective to reduce mental retardation by 50 percent within this century. This aspiration became a formal declaration of policy when President Nixon issued an executive order to that effect. The objective was, and still is, a very ambitious and bold undertaking, especially when one considers the vast heterogeneity of both cause and effect associated with mental retardation. Although 30 years may have seemed to be a perfectly ample time frame in which to accomplish the goal, the very complexity of the problem is sobering. Many have wondered aloud whether this projection was an unrealistic dream.

As we have pointed out, when such a far-reaching and major objective is set forth as public policy, it is bound to come under close and critical scrutiny. Questions have been raised as to whether the goal is attainable. The main concerns include: (1) lack of an adequate scientific knowledge base; (2) vague understanding of incidence and prevalence; and (3) reluctance to implement policies that cut to the heart of the major impediments to realization of the goal.

Regarding this last consideration, we understand that mental retardation is more than a biologic manifestation. It is part of our sociology, our political structure, and our system of values. Thus, it was with these considerations at the fore that the PCMR set forth a corollary objective: to reduce incidence and prevalence of mental retardation associated with "social disadvantage" to the lowest possible level. The theme of this conference and the revised Guide is to address prevention of mental retardation within the context of socio-economic considerations as these may, on the one hand, be implicated as root causes of mental retardation, and on the other hand, be regarded as major impediments to a national effort to prevent mental retardation and other disabilities. If we are to achieve the goal of reducing mental retardation within this century, then the time has arrived to look under the carpet where we have tended to conceal so many of the knotty and difficult problems. We can meet the challenge. But it will not be easy, and time is slipping away.

Our analyses have led us to conclude that obstacles to a serious and concerted public effort have always been and continue to be rooted in the social, economic, and political vectors that condition public policy. In the draft document we have elaborated on these issues that I shall mention here:

1. The absence of a strong, well-organized and outspoken public constituency that places prevention at the top of the agenda.
2. A national health care program that addresses the needs of all citizens, not just those who can afford, but includes those who can not afford.

3. Fragmented prevention-oriented services and support systems within state and Federal structures.
4. Lack of an integrated national database from which to draw policy recommendations and to form an effective plan of action.
5. Poorly coordinated funding of prevention initiatives.
6. Lack of documentation regarding epidemiologic concerns, assessments of outcomes, and evaluation of effectiveness at the local level.
7. Inconsistency in eligibility requirements for different services between and within states.
8. Budgetary constraints resulting in cutbacks of needed and cost-effective programs.
9. Belief systems and ethical concerns that pose threats to prevention programs, for example, prosecution of pregnant women addicted to cocaine.
10. Competition for resources among social programs, making adversaries of those who naturally share the common cause.

Now, it is not to be denied that we have all been witness to notable achievements in public health areas and in greatly expanded scientific and medical knowledge. Indeed, these achievements have improved the quality of life and longevity of many people, as Dr. Alexander pointed out so well. But I assert that there is a darker side to this generally sanguine, but somewhat distorted picture. Over the past decade, we have all seen trends emerging that must engender concern, for they entail enormous social and economic costs. Significant reversals are apparent in specific and general health indicators that affect children and mothers. Cutting entitlement programs and services may mean saved dollars, but lost lives. Actually we have not saved dollars at all, for even in the short-term, the costs are enormous. It does not require an advanced degree in economics to figure that out.

With the new morbidity model, we attempt to address specific environmental, social, and economic factors that are increasingly affecting the immediate well-being of infants and children, with long-term consequences. Also, in an effort to extract "signal" from "noise," we propose this model to suggest specific recommendations aimed directly at prevention.

An array of biological, behavioral, and sociocultural variables interact to produce or amplify many diverse threats to children's physical, intellectual, and social well-being.

Even in instances where particular biological causes are clearly implicated to produce adverse health outcomes (e.g., PKU), other medical, behavioral, social, and personal characteristics often are inextricably woven into the fabric of development.

While we may not yet fully understand the patterns and processes by which developmental perturbations occur, we do know that we are dealing here with multiple-risk problems. Accordingly, uncertainties about etiology and symptomatology, and how to treat and prevent health and developmental impairments, are not likely to yield to simplistic explanatory models. How then can we go about reducing uncertainties within a coherent and comprehensive approach to prevent these problems?

Evidence is becoming increasingly abundant that explanatory perspectives involving biomedical, environmental, and psychosocial variables linked together yield the most valid and useful bases from which to develop, test, and articulate comprehensive theories of causes and effects, and to suggest interventions and prevention strategies. [See Figure 1] The concept of the New Morbidity is intended to provide an integrated perspective with which we can begin to organize knowledge about how and why biomedical, environmental, and psychosocial factors affect children's health, development, and well-being. Within this conception, mental retardation for example, is a "symptom," among others, of underlying biological and social stressors.

The concept of New Morbidity, originally described in the 1970s by Dr. Haggerty and his associates, is elaborated in an effort to generate a coherent model that embraces a broad array of increasingly prevalent contemporary psychosocial and health problems. While biomedical features clearly play a prominent role with respect to many adverse health and developmental conditions, our expanded model emphasizes poverty and other social factors as crucial determinants.

This generalized scheme was derived from analyses of trends and relationships suggested by a large number of research studies and numerous databases pertinent to New Morbidity-related causes and effects. Even with the simplified version shown here, there is clearly a great deal of work yet to be accomplished to specify the nature and extent of relationships proposed. But we do have a start and some answers. In other analyses we obtained correlational indices with respect to certain outcomes, such as prenatal exposure to cocaine or pediatric Acquired Immune Deficiency Syndrome (AIDS). We can disentangle causes from effects and demonstrate the relationships in quantitative and directional terms. Although our model is presented here in a linear fashion, it is important to keep in mind that in an individual's real-life environment and biological vulnerabilities such as low birth weight, tend to combine with environmental contingencies such as poverty.

As displayed, the model encompasses five major classes of variables. For ease of analysis and theoretical elaboration, we have attached a general label to each. They obviously operate within a continuous feedback loop such that, for example, a specific outcome may condition the risk attendant to a particular predisposing variable.

1. Predisposing variables include three subcategories: (a) demographic characteristics--race, education, age, marital status, and Socioeconomic Status (SES); (b) behavior features including personal habits and beliefs; and (c) genetic/biologic factors. All are linked to pre- and postnatal health and developmental problems. They act in concert with catalytic influences such as poverty and other social/political variables that mediate direction and degree of influence.

2. Catalytic variables include poverty, acute and chronic, relative and absolute, along with political and social conditions.

Between 1979 and 1989 there was a 17 percent increase in the number of individuals living below the poverty line. [See Figure 2] Now, at least 20 percent of all children live in the grip of poverty, including 43 percent of black children, 35 percent of Hispanic children, and 14 percent of white children. Of all children under 3 years of age, one in four is poor, totalling about 3,000,000. Moreover, the length of time in poverty is gradually increasing. For children living in female-headed households, the number who were poor reached over 50 percent in 1989, and for those women under 25, the rate is 75 percent. Breakdown by group is 42 percent white, 73 percent black, and 47 percent Hispanic.

Children who live in poverty are at a greatly heightened risk to suffer from one or more disabilities. Both neonatal and postnatal mortality are increased among low-income children, as is low birth weight--the best proximal predictor we have yet identified.

3. Resource Variables include educational, medical, and social supports and programs aimed at enhancing the physical, intellectual, economic, and emotional development of at-risk children and their families, empowering them to take advantage of opportunities that affect health and well-being. Specific examples include WIC, prenatal care, childhood immunization, quality daycare, family, child, and adolescent mental health

services, vocational skills training programs, and parenting skills programs.

But, where are the resources? WIC programs are being drastically cut or eliminated for large numbers of women and children at the same time poverty rates are going up. Less than 60 percent of women who qualify actually receive WIC benefits. Immunizations for many childhood diseases have declined since 1985, particularly for certain subgroups who are already in harm's way. Parts of the country are right now experiencing a measles and Rubella epidemic, leaving many children brain damaged. Up to one million children run away each year. As many as 200,000 become involved in high-risk behavior such as drug use and prostitution. Fewer than half the children in need are enrolled in Head Start; only half the children who qualify receive free school lunches.

Between 1979 and 1989, the proportion of mothers who began early prenatal care remained unchanged, and over the past five years there has been a 1 percent increase for delayed or no prenatal care, again a trend that is selective. [See Figure 3]

4. Proximal variables. These variables are most immediately reflected in the health status of the newborn infant. Low birth weight (LBW), intrauterine growth retardation, and preterm birth are all examples of proximal conditions that contribute to infant and childhood morbidity. There has been a virtual standstill in the nation's attempts to lower the incidence of LBW.

In 1988 the overall proportion of LBW infants was 6.9 percent. [See Figure 4] This translates into more than a quarter of a million babies annually. There is a significant racial disparity (white babies = 5.6 percent, black babies = 13.0 percent). LBW infants are nearly 40 times more likely to die in the neonatal period when compared to normal weight infants, and are at five times the risk of death during their first year. Neurodevelopmental handicap risks are increased threefold. Women under 19 years of age accounted for 13 percent of all births in 1989, but for over 17 percent of all LBW infants. Last year teenage pregnancies increased significantly, about 6 percent.

Scott and his colleagues in Miami are now conducting a birth weight study involving almost 21,000 children. Preliminary results show that risk of severe disabilities among children under 1,500 grams was 55 per 1,000 compared with a risk of three per 1,000 of the total study cohort.

In 1989, 47 states and the District of Columbia adopted the revised U.S. Certificate of Live Births. This will provide a national data base relating to medical and social risk factors. Better understanding of the etiology of LBW as well as the large racial differentials should be a major breakthrough as a result.

5. Outcome Variables represent an array of long-term or permanent adverse health and developmental conditions. These include: chronic health problems, developmental disabilities, educational failure, and various acute and chronic psychiatric and/or emotional disabilities. At the clinical level these conditions may seem disconnected, but as we and others have shown, they cluster. Adversity begets adversity.

For purposes of illustration, I shall briefly address the problem of children with Human Immunodeficiency Virus (HIV) infections.

Pediatric AIDS is becoming a leading killer of children and a major cause of mental retardation. [See Figure 6] We have attempted to model the epidemic on data from the CDC, as shown in the slide from an August CDC report. Even though the demographics of AIDS are rapidly shifting to include many heterosexual women of childbearing age, very few primary prevention programs target women at risk for HIV infection. The changing demographic patterns of this disease ought to be of great concern to policy makers, but our surveys show this just isn't so.

Women with HIV infection often do not obtain optimal levels of prenatal care, if any, because of other adverse circumstances. They may also suffer from inadequate nutrition, intravenous drug use, economic adversity, and psychosocial deprivation. While a few projects offering primary health care are funded by the Office of Maternal and Child Health, pediatric HIV-related outreach and follow-up rarely occur for children with HIV and their families. Across the United States there are a number of local model programs, but together, they hardly touch the problem.

Total pediatric AIDS-related hospital care costs will amount to $200 to $300 million in 1991. Each outpatient child with HIV will need an average of two to four medical visits per month at a cost of about $800 per month. For perinatally AIDS-infected infants who are active Medicaid users, estimated annual costs range from $18,000 to $42,000 per child. Twenty percent of total health care costs for these children is related to their social circumstances.

Many of these children, like those prenatally exposed to drugs, are "boarder babies," abandoned in hospitals or assigned to a congregate care facility. Lack of sufficient socially-oriented research support and the absence of a national collaborative study has resulted in sketchy knowledge of the full obstetric and pediatric implications of AIDS. Belief systems are also an incredibly difficult obstacle. Existing state policy formulations are spotty and ambiguous. While Federal law has provided some desirable policy content, policy-related processes remain underdeveloped.

Through our study of policies in all states, we have found that the national profile of state pediatric AIDS policy development is extraordinarily uneven. The sophistication of public policy development is strongly related to actual seroprevalence rates. To our dismay, very few state spokespersons were aware of the link between HIV infection and developmental disabilities, although the biology of this effect is understood to some extent. AIDS-related policy-making in public schools is exceedingly complex. There is wide variation in opinions about what should be done educationally about children with AIDS. Policies vary widely. Moreover, there is no linear relationship between policy and practice. What we say is not always what we do.

CONCLUSION

Evidence is overwhelming that recent trends affecting the health of children are not conducive to development, including such diverse public health aspects as prenatal care, low birth weight, immunizations, infectious diseases, abuse and neglect, violent behavior, and accidents. Poverty is not good for children. These facts do not seem to drive contemporary policy. The question is, then what does? That is a question we seek to address in the Guide.

Politics, poverty, and disadvantage have extracted a terrible toll on our children. Problems associated with the New Morbidity are complex, profound, and frequently irreversible in their effects on individuals, families, and society. The human and economic costs of allowing these influences to remain unresolved far outweigh the costs of investing time and resources in research, treatment, and prevention. As society becomes more complex and pressured and as greater numbers of individuals and families find themselves facing economic, social, and environmental travail, more and more children will become the victims of psychosocial, developmental, and behavioral problems. The ever-progressing incidence of New Morbidities will undoubtedly necessitate a strong national and local commitment to more preventive health care services, social services, and educational awareness programs. Terribly sensitive but diverse issues such as income distribution, screening for diseases, improved housing, health insurance, and quality day care will have to be addressed fearlessly and equitably.

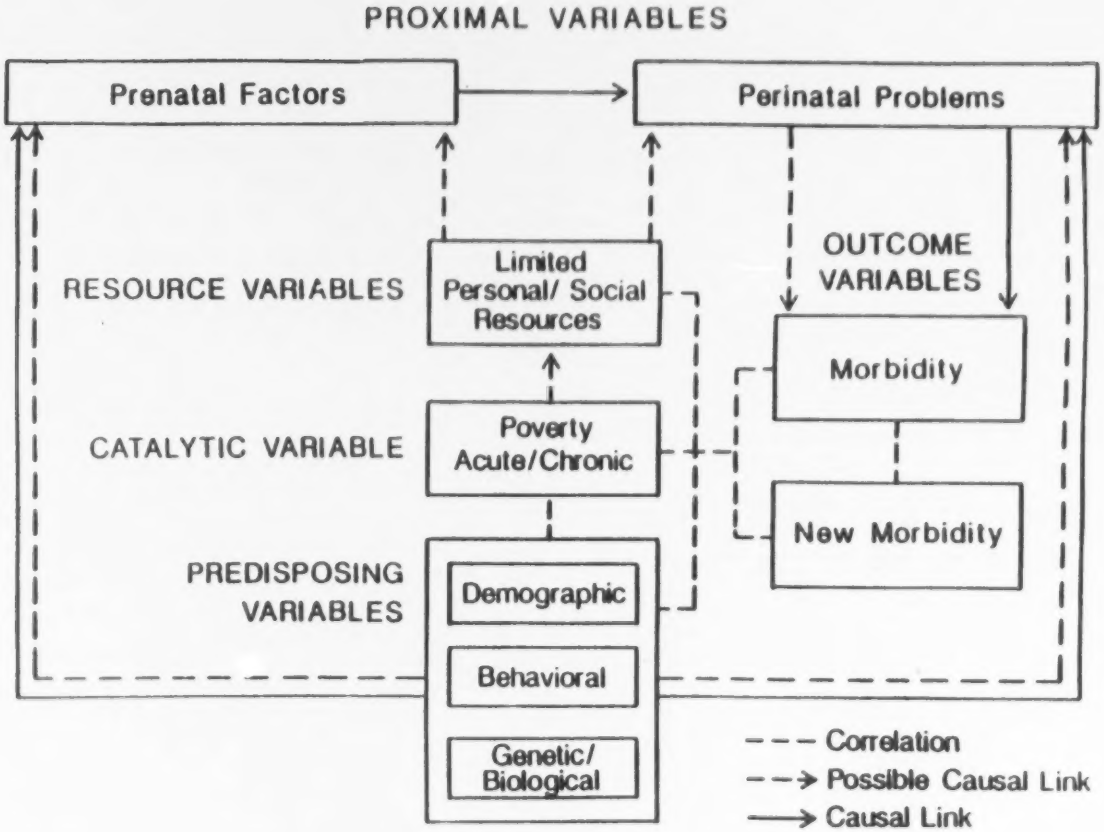
While there are some localities in the United States which facilitate routine preventive care, the fact is that we do not have a comprehensive, integrated national health policy especially for children. This is all the more dismaying because we do possess the knowledge base with which to implement cost-effective public health and educational programs. But we do not have in place the effective integrated systems to ensure continuity of programs and accessibility to services. Rhetoric alone will not solve these problems. There is light at the end of the tunnel, but it remains dim.

Solutions to the myriad problems that give rise to the New Morbidity do not come easily. Indeed, the Gordian Knot of social, economic, medical, and psychological factors that produce children at risk has turned the talents of many of the very people who might disentangle it toward other more immediately solvable problems. In many instances, programs have been instituted that, like the babies they were intended to serve, failed to thrive.

As a nation we may be lured into the pretense that the poor, disadvantaged, and disenfranchised are condemned to an intergenerational cycle of despair and deprivation; that they are somehow committed to a fate of their own, one disconnected from ours. Should we let poor children suffer and die because they are a draining surplus on our society? That conclusion may make for good arithmetic, but terrible morality. Our contemporary, perfunctory, and dispirited treatment of many poor children does not enlighten our consciousness nor amplify their cries of anguish and despair. To ignore these families as the inevitable consequence of human variability, is an illusion that is morally and socially harmful and wrong. This is an injustice that cannot be contained within the walls of conventional social practice. To adopt philosophies and policies that separate them from us is an injustice that reflects on our values and social order. We race toward a moral crossroad, because if the children do not have us, what hope have they?

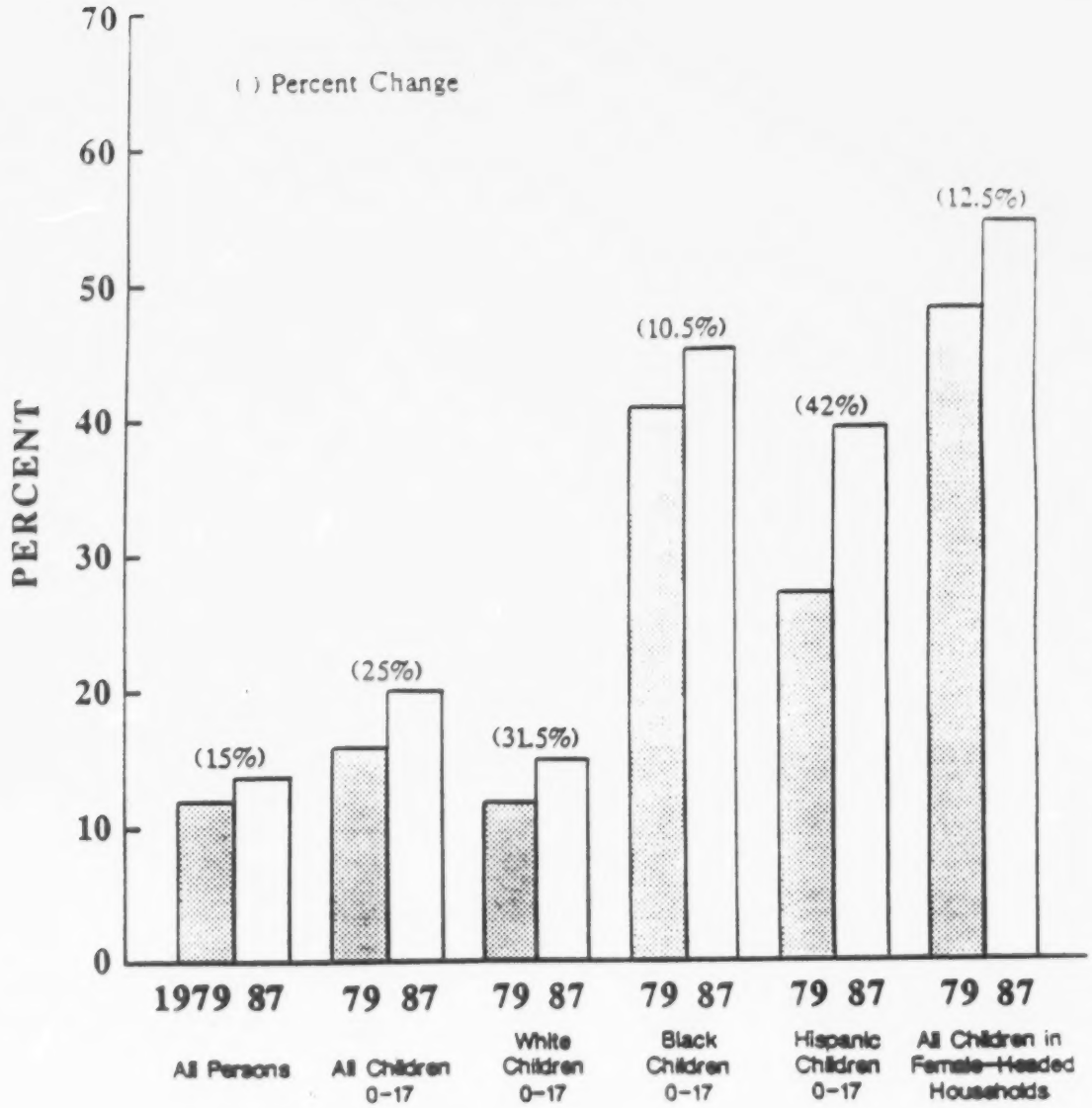
I'll conclude with a quote from Hubert Humphrey: "The measure of a nation is how it treats people in the twilight of life, people in the dawn of life, and people in the shadows of life."

Figure 1 (Baumeister)



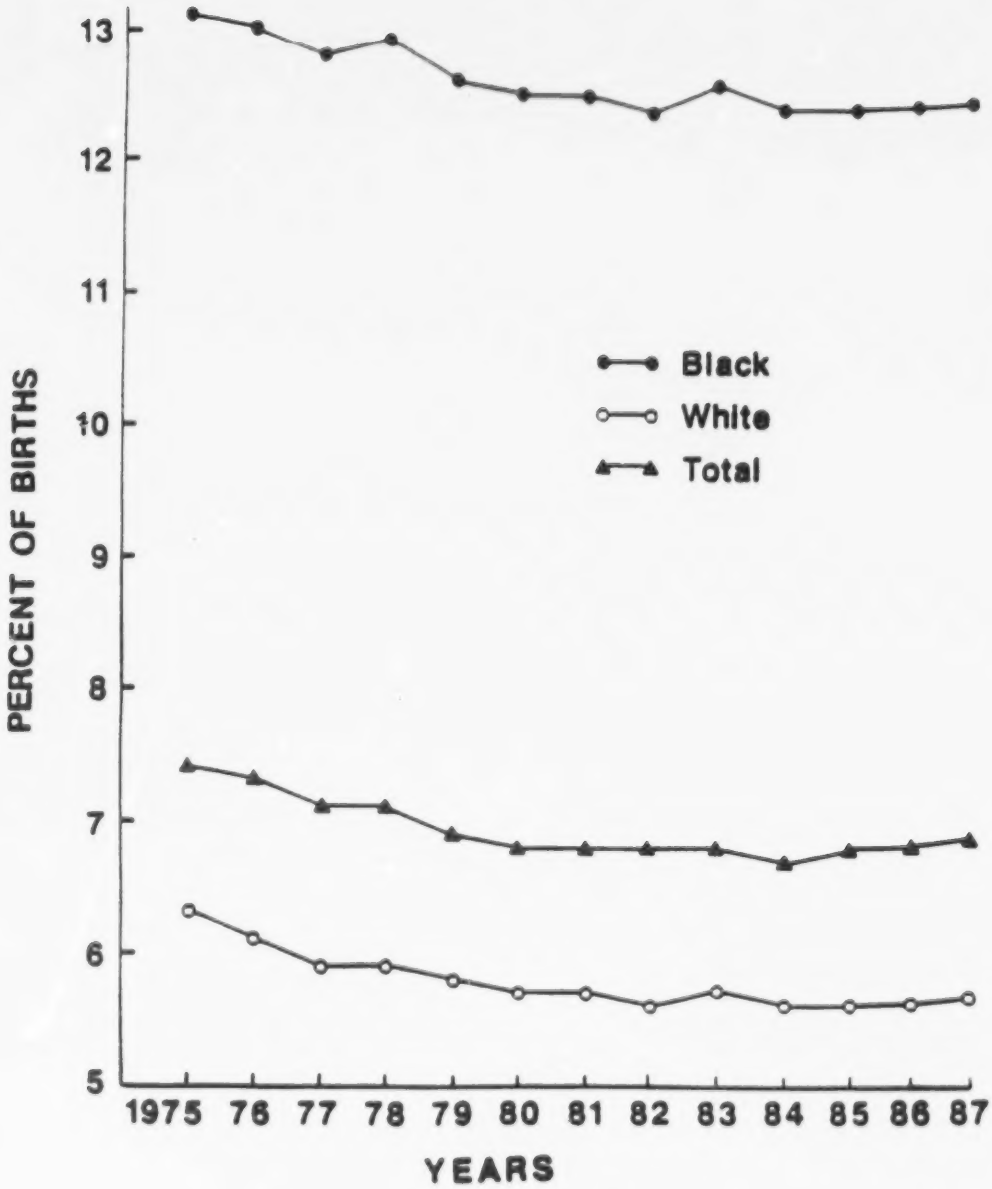
Generalized Model of the New Morbidity

Figure 2 (Baumeister)



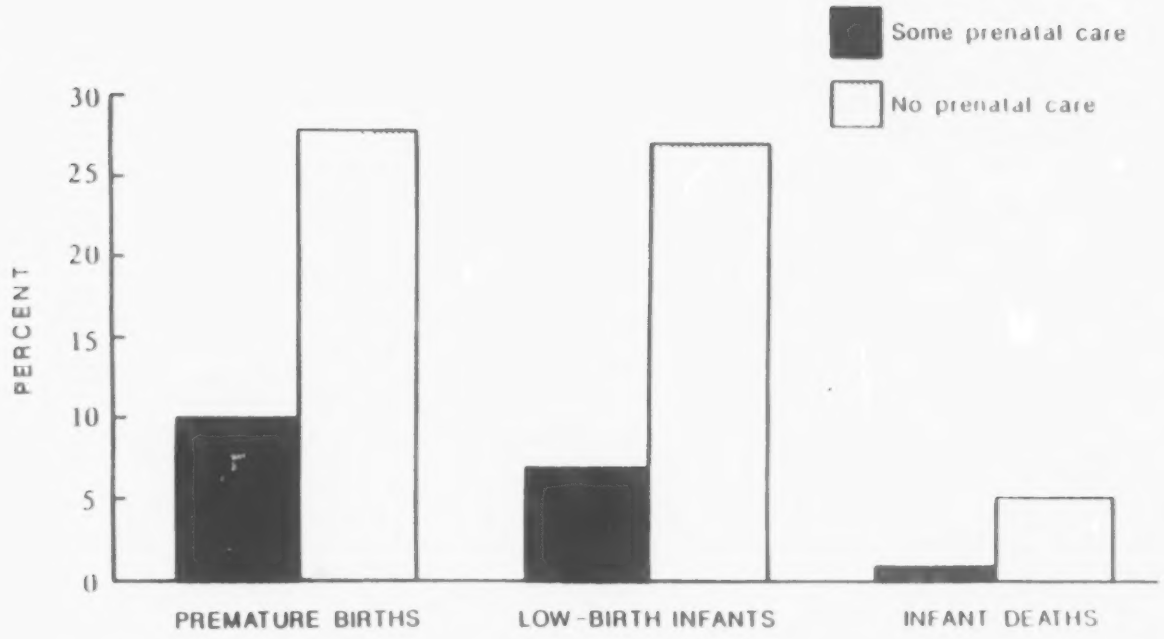
Percentage of population below poverty level by selected characteristics, 1979 and 1987. (Statistical data from: Statistical Abstracts of the United States, 1989, Bureau of the Census, Washington, DC.)

Figure 3 (Baumeister)



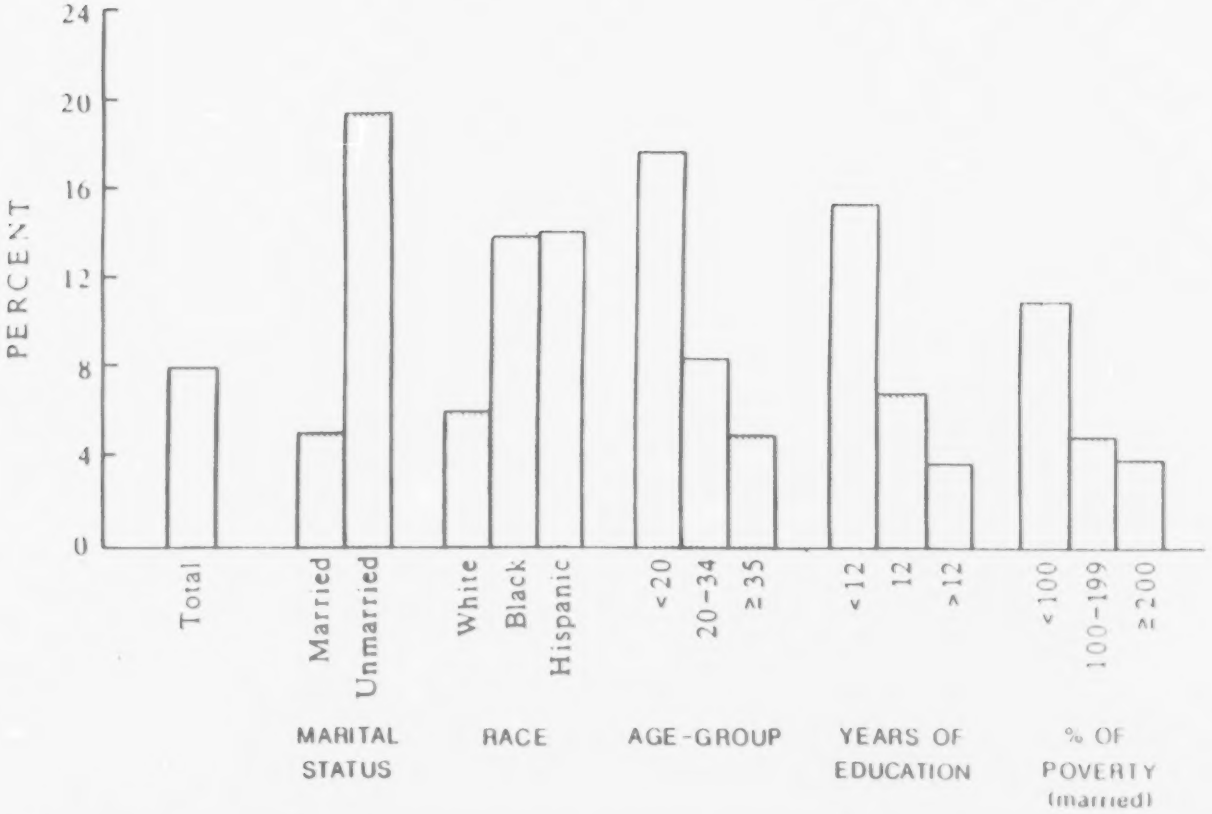
Percentage of low birth weight infants from total live births in U.S. 1975 thru 1986 (Source of data: Statistical Abstracts of the United States, 1987, Bureau of the Census, Washington, DC, and Monthly Vital Statistics Report, Vol. 37, No. 3, 1986.)

Figure 4 (Baumeister)



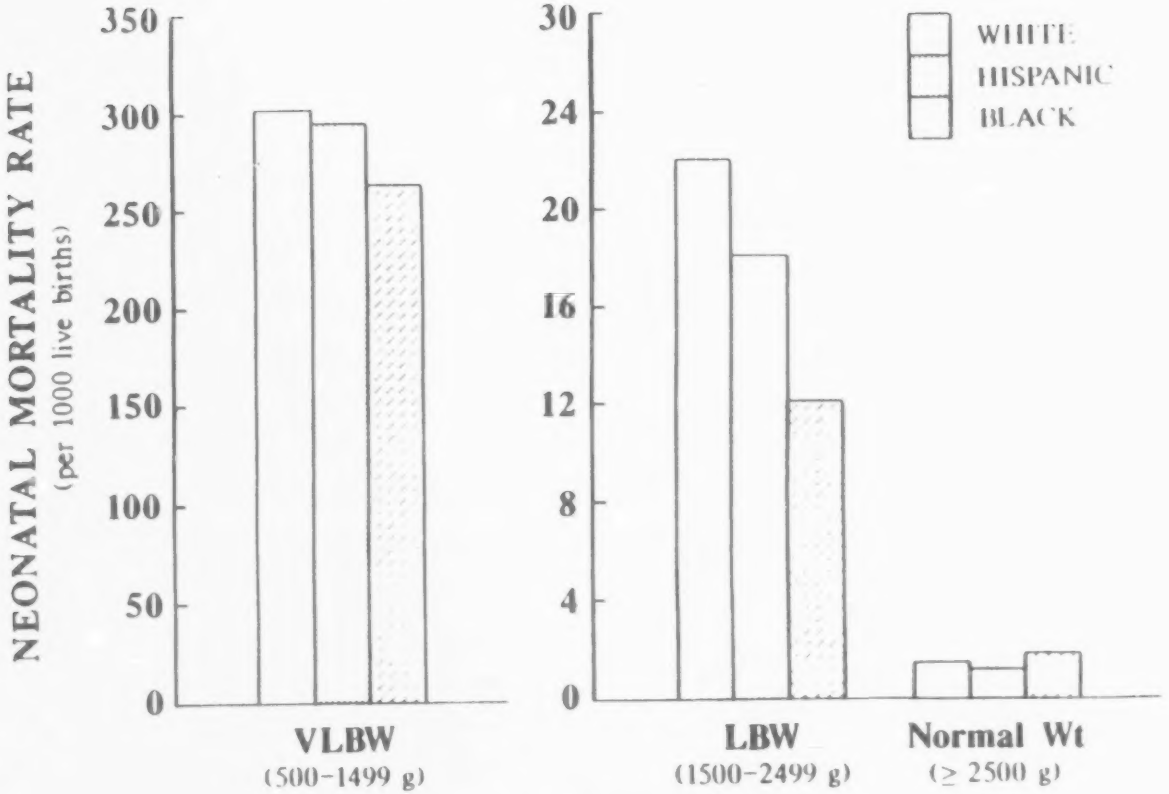
PERCENTAGE OF ADVERSE BIRTH OUTCOMES RELATIVE TO PRENATAL CARE.
(From Blessed Events and the Bottom Line: Financing Maternal Care in the United States. The Allan Guttmacher Institute, New York, 1987.)

Figure 5 (Baumeister)



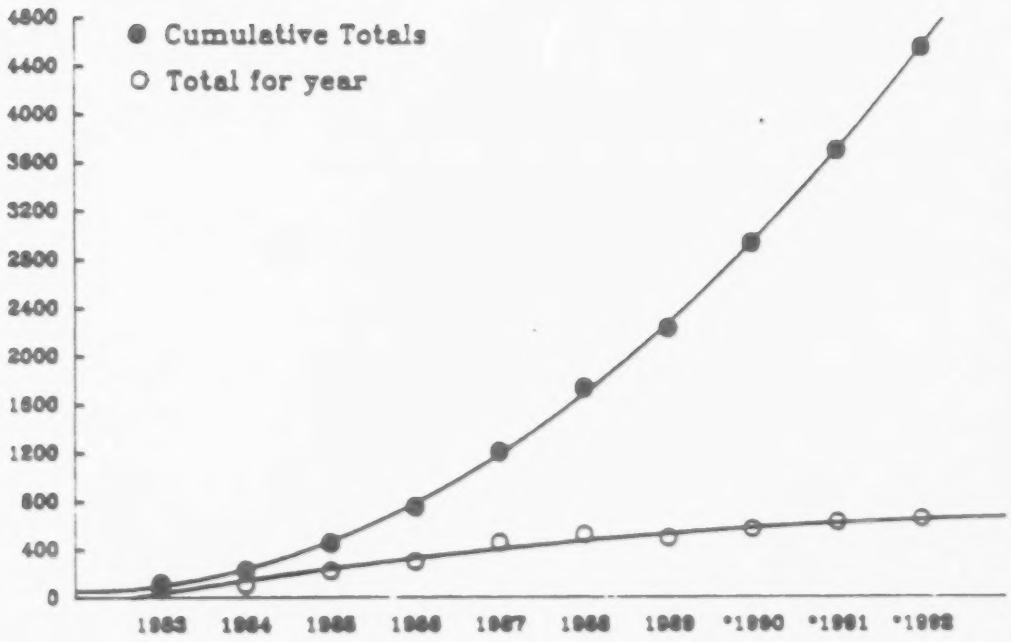
PERCENTAGE OF MOTHERS WHO HAD POOR OR NO PRENATAL CARE BY SELECTED CHARACTERISTICS, 1980. (Adapted from Blessed Events and the Bottom Line: Financing Maternal Care in the United States. The Allan Guttmacher Institute, New York, 1987.)

Figure 6 (Baumeister)



Racial Differences in Neonatal Mortality.

Figure 7 (Baumeister)



*Indicates projected totals.

Figure 8 (Baumeister)

Expected years of childhood poverty out of first 15 years of life for the year 1984. [Source of statistical data: Children in Poverty (Report No. WMCP 99-8), May 22, 1985, Congress of the United States, Washington, DC.]

EFFECTIVE STRATEGIES FOR PREVENTING MENTAL RETARDATION AND RELATED DISABILITIES ASSOCIATED WITH SOCIO-ECONOMIC CONDITIONS

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In 1972 the President's Committee on Mental Retardation set a major national goal to reduce the incidence of retardation by 50 percent before the end of this century. As the end of the century draws near, it is clear that this goal will not be met, nor do I believe, will it ever be. Even if we learn to identify every defective gene and physical process responsible for the many types of organic retardation--and find a way to fix them all--we will only have cured about one third of the population who have subnormal intelligence. The rest are retarded because of the variability in the gene pool of the human species. This variability guarantees that no matter how we define intelligence, people will differ in how much of it they possess. There will always be individuals who have superior intellectual ability, just as there will be those whose ability is inferior. While we cannot do much about their genetic draw, we can hope to influence the full use of given abilities in everyone.

I realize that the cause of retardation where no organic problem is apparent is controversial and remains the most perplexing problem haunting both researchers and theorists. By now we have come close to consensus that this form of mental retardation reflects some complex interaction between genetic and environmental factors. There are still some who favor the genetic explanation and believe that with advances in technology, researchers will be able to detect organic impairment in persons now thought to be non-organically retarded. One of the best examples of this is the discovery of Fragile X Syndrome, a disorder that ranks second only to Down's Syndrome as the leading genetic cause of mental retardation. On the other side are those who still believe that a poor environment is to blame for poor intellectual functioning. By providing low-functioning children with an extremely stimulating environment, we can ameliorate any adverse conditions in both nature and nurture.

This extreme environmentalism was actually in vogue not long before the President's Committee formulated its 1972 goals. Many of the educational interventions

initiated in the 1960s were the product of a naive faith in the malleability of intelligence. Throughout the 1960s social scientists were enamored with the claims of Hunt and others that IQ could be radically altered by such simple procedures as hanging a mobile over a baby's crib. If intelligence could be increased so easily, all we had to do for children who were at risk of performing poorly in school or failing their IQ tests was to give them a dose or two of this concept and that experience. This enrichment would enable them to achieve as much as their middle-class peers and make them immune to any problems posed by the continuing hunger and poverty in their lives. These opinions were bolstered by research findings that just about every early intervention program increased IQ scores by at least 10 points, some in as little as six to eight weeks. If intelligence was so sensitive to environmental input, it is no wonder that the President's Committee concluded that the environment was responsible for the high incidence of mental retardation among poor children, and that improving their environment was a sure solution.

What happened next could have been foreseen by any student of history. Extreme but easily understood, views usually attract many followers for a time, but their inevitable failure to solve complex problems leads to disillusionment and a swing of the pendulum to extreme views in the opposite direction. We saw this happen with the state institutions and training schools which were originally established with the goal of providing the newest and best mental orthopedic experiences to make retarded persons normal. But this did not happen, and professionals were quick to adopt the opposite belief that nothing could be done to alleviate mental retardation. The training schools became human warehouses remote from the rest of society and the treatment of retarded people entered a dark era. A similar about-face occurred at the end of the 1960s when it was discovered the amazing IQ gains evident after early intervention were quick to fade away when children began regular schooling. Soon the misguided belief that slum children could be educated to test just like middle-class children was replaced by pessimism as to whether they could be helped at all. The opinion developed that early childhood programs were a waste of time and taxes. Even our nation's popular Head Start program was threatened with termination.

We had been caught in an environmental spell that bewitched us into believing that we could cure most cases of mental retardation simply by providing the right kind of experiences. These unreal expectations were based on only a partial understanding of the determinants of subnormal intellectual functioning and led to disappointment and resentment. Fortunately, most workers have now adopted a more balanced view of the etiology of mental retardation as the interplay of both genes and the environment where they are expressed. The continuing transaction between children and their environments

can certainly alter cognitive development for better or for worse, but it cannot restructure intellectual endowment.

A twist on the environmental extremism position has surfaced in the view that the perception of mental retardation is an environmental creation. That is, retardation is a social phenomenon based on whether or not individuals are capable of meeting social expectations. We have all heard of the six-hour retarded child--a child who is labeled retarded in school but displays perfectly adequate social adaptation after school hours. Another example of the socially constructed nature of mental retardation is the higher prevalence rates among school-aged children compared to those in the pre- and post-school years. The reason is that cognitive demands are greater for the child in the classroom than they are for the preschooler or young adult who function in a broader environment where activities that are within their capabilities are available. Labeling theorists carry this environmental definition a step further and assert that mental retardation is created by assigning the label to the child. If this were true, mental retardation could be reduced by 100 percent by ruling that we never use that label. This, of course, would not help retarded persons at all and could hurt them by denying helpful services and appropriates education and training. This is exactly what the Granats in Sweden and Don MacMillan have been finding among mildly retarded persons who are not identified because well-meaning professionals are shunning the label. When they lose their advocates and support systems, they can drown in the mainstream.

But we do want to help retarded persons--no longer in the sense that we promise to "cure" them, but that we hope to enable every retarded person to function as well as his or her abilities permit. Why is it that many retarded persons are successful in holding jobs, meeting family responsibilities, and contributing to their communities, while others with equal or higher IQs require constant supervision in group homes and sheltered workshops? Again, the answer is in their environment, but this time we do not blame it for causing their low intelligence but for their apparent level of functioning. There is a sizeable body of literature which shows that many retarded persons develop atypical motivational traits such as high needs for social reinforcement, strong social approach and avoidance tendencies, and a response style of learned helplessness. To the extent that deficits in performance occur for motivational reasons, practices aimed at reducing motivational problems will improve performance levels. For example, there is ample evidence that children from lower-class homes generally perform relatively poorly on tests of intellectual competence and achievement regardless of the content features of the tests used. There is also evidence that their test scores rise when motivational barriers are removed by simple interventions like rewarding their performance or providing a "warm-up" period to put them at ease with the examiner and testing situation. Retarded children from lower-class homes can also be expected to be wary of the unfamiliar

demands of the test and the strange examiner, but have the added impediment of a history of failure experiences and a lack of confidence in their abilities. For them, something more than a small toy reward or the opportunity to play a game with an adult is required to encourage their best performance. For the majority of retarded persons, their best performance should certainly be adequate to meet the requirements of everyday living. Most retarded people have mental ages in the 9 to 12 range. Although these MAs do not predict success in college or high-tech occupations, they do indicate the intellectual wherewithal to achieve an independent and productive lifestyle. Thus, efforts to impart more intelligence may not only be destined to fail, they may be unnecessary.

It seems clear that the most effective interventions will be those that help retarded children use the intelligence that motivational factors cause to lie dormant, rather than those that attempt to add more IQ points to the child's potential. There are several sound arguments for this approach. While the subsystem underlying intelligence may be a poor candidate for environmental manipulation, other subsystems are highly influenced by experience. These include those systems affecting socialization, motivation, and personality development. Besides the fact that these processes are more plastic than IQ, they have more of a bearing on social adaptation. IQ is a much better predictor of school success than of life success, while personality attributes have a solid influence on both. Although a motivational approach holds no promise of a dramatic cure for mental retardation, it can provide the means of helping retarded persons use their intellectual capacities optimally. This goal is not the stuff that headlines are made of, but it is realistic and allows us to respect individual differences.

Our best course of action is to offer interventions designed to enhance the social competence of children whose poor environments may not sustain their developmental needs and leave them at risk of performing poorly on the tasks ahead of them. Unfortunately, social competence is a construct with no universally accepted definition. Therefore, there are no clear procedures for addressing it and no adequate measurement tools. Yet most professionals share a sense of the components of competence and we can work from these at this time. Broadly defined, social competence includes physical and mental health provided by adequate nutrition, preventive care, and the encouragement of coping resources. Formal cognition abilities also influence competence, as does the mastery of academic skill and achievement areas appropriate to the child's age. Finally, healthy social and motivational development will allow the child to project competence in a variety of settings. A number of early intervention projects have been mounted to address at least some of these aspects of social competence, and they have shown a variety of impressive, long-lasting results.

Two well-known programs were designed for the specific purpose of preventing mental retardation in at-risk children. The Milwaukee project targeted black infants of retarded mothers who lived in a very poor inner-city area. Beginning in infancy, until they entered first grade, the children attended a full-day program five days a week. Highly trained staff provided intensive educational enrichment that was personalized to the specific needs of each child. The mothers received some training in job, reading, and home management skills, but they were essentially replaced by the center teachers for much of the child's time. The children began grade school with about 20 IQ points more than a comparison group from similar, high-risk backgrounds. In the last follow-up when the children were about 14 years old, Garber reported that the IQ advantage of program graduates had narrowed to 10 points. Still, the group's average IQ was 101, well within the normal range. From the beginning of school, however, their academic performance did not reflect their abilities. Although their reading and math scores were considerably higher than those of control children, they were considerably below national norms. Nearly one third of the project children demonstrated social or behavioral difficulties in school. Apparently their bolstered intelligence did not ensure their smooth transition to the elementary school environment. Garber and his colleagues have cited the failures of inner-city schools to activate the potential of poor children, but they have also noted persistent home problems and motivational difficulties, such as poor self-concept and negative attitudes toward school, as explanations for the lag between performance and ability. The Milwaukee project stands as proof that increased intelligence does not guarantee better behavioral outcomes and suggests that it may be more productive to work within the child's environment rather than replace it.

The Abecedarian project was another very intensive intervention conducted at the Frank Porter Graham Child Development Center in North Carolina. The researchers hoped to demonstrate that developmental retardation could be prevented by identifying pregnant women whose expected children were likely to be at risk of eventual school failure. The program provided child care, a specialized educational curriculum, pediatric care, and some family support services if the parents requested them. Most of the children had completed six full years of intervention.

Like the children in the Milwaukee project, the experimental group began school with near-normal IQs, but their achievement in school did not match their potential. Over 25 percent of the children failed a grade in the first three years of school, and nearly half placed in the lowest quartile on reading achievement tests. The children who received both preschool and school-age intervention did perform better than controls, suggesting that continued support may improve poor children's school performance more than a shorter program. Yet the relatively small IQ gains may be possible with less

intrusive and less costly programs, and stronger benefits may be reaped by programs that pay more attention to social competence and to the family in which the child is raised.

The Perry Preschool, or High/Scope Project, was one such effort designed to compensate for mental retardation associated with "cultural deprivation." It began later and was not as intense as the Milwaukee and North Carolina efforts, but it did more to involve parents in their child's education. Low-income, black 3 and 4 year olds attended a preschool where they received a high quality, cognitively oriented curriculum for one to two academic years. Teachers conducted weekly home visits to keep parents apprised of their child's activities and to encourage participation in the education process.

Again, project children began elementary school with significantly higher IQs than controls, and again, this IQ advantage disappeared during the first few years of school. However, follow-up studies of children up to age 19 show a number of positive outcomes indicative of good social competence. Compared to controls, program graduates showed better attitudes toward school, had lower rates of grade retention and placement in special education, and performed better on achievement tests and report cards. They also had better high school graduation rates, higher employment, lower use of welfare, and were less likely to be involved in delinquent or criminal behavior.

The High/Scope group's interpretation of these long-term effects is that the preschool program resulted in a more positive reaction by kindergarten teachers, leading to a stronger commitment to schooling, followed by better school adjustment in later grades. Victoria Seitz has offered an alternative explanation which emphasizes the role of the extensive home visitation component of the project. She hypothesized that, as a result of their involvement, parents became better socializers of their children across the intervening years between the time the preschool program ended and longitudinal data were collected. Early in their children's lives, parents gained experience in building proactive relationships with teachers and in providing a supportive home environment, practices that may not have raised IQ scores but certainly helped to shape competent behavior.

The impact of parental support and effective family functioning on social competence is supported by the outcomes of several interventions that focused more on parents than on children. I will mention two examples. The goal of the Yale Child Welfare Research Program was to provide support to mothers raising young children in high-risk environments so they could devote more of their energies to parenting. Services included home visits by clinical and health professionals who counselled the mothers in solving practical problems such as how to secure adequate food and housing and making decisions about future education, career, and family goals. Program workers also acted

as liaisons with other local services that could benefit the families. For the children, pediatric services and optional child care were offered, but there was no formal educational program.

At the 10-year follow-up, intervention mothers had obtained significantly more education than had control group mothers. Almost all of the intervention families had become self-supporting by the time their firstborns were 12½ years old. Intervention mothers also had fewer children and spaced their births more widely. They appeared to be more involved in their children's education. As a result, program children had markedly better school attendance and adjustment than those in the control group. The Yale project was certainly successful in improving children's behavior and in raising the quality of life for these families, both achievements of enduring value.

Like the Yale program, the Houston Parent-Child Development Center offered a parent-oriented intervention. The program sought to enhance school performance and to reduce the incidence of behavioral problems among poor, Mexican-American children. The major focus was on the mother/child interaction in the family setting. Paraprofessionals conducted home visits to provide the mothers with information on child development and to give advice on coping with stress and creating a stimulating home environment. Entire families attended many weekend workshop sessions to involve fathers and siblings. The children attended a typical half-day nursery school for one year.

By the time they were in grades 2 to 5, intervention children had higher scores on tests of basic skills, showed fewer aggressive, acting-out behaviors, and were less hostile and more considerate than controls. Less impressive outcome data were found when the children were in grades 4 through 11, about seven to 15 years after program completion. Although some positive, significant outcomes were found for the oldest group of cohorts, the earlier differences in aggressive behavior were not apparent. Nonetheless, parents who participated in the program had higher Hollingsworth SES scores and reported higher job and education aspirations for their children. These positive program effects, which one would expect to indicate a more stable and supportive home environment and a greater commitment to school, merit our scrutiny as the children continue their development, since these two factors appear to be strong mediators of social competence.

Many, many other reports of early intervention programs prove that IQ gains are fleeting, but that positive, lasting changes in family and child functioning are possible. Where did these improvements come from? We discovered a long time ago--from the early days of Head Start--that the most successful intervention efforts are those that include the child's family. The reasons for this are obvious. Regardless of their IQ

scores or income levels, parents have the first and most lasting influence on children. Families do not decide to care for a child only during infancy, the preschool years, or for any fixed period of time like intervention programs do. Families do not provide one type of support for one aspect of development, but provide many supports that change in form and content as the child grows. Although Karl White and his colleagues suggested at a recent SRCD meeting that views concerning parent involvement may have taken on a life of their own, common sense tells us that if children are influenced by their environment, and families constitute a significant part of that environment, then environmental intervention must include the family.

This type of thinking was the basis for Urie Bronfenbrenner's now widely accepted ecological approach to human development, which envisions the environment as a set of nested proximal and distal settings within an overall interactive system. If the explanation for certain behaviors lies in the interaction between characteristics of people and their environments, we must change environments in order to change behavior. And if one environment is affected by and affects another, then a truly broad intervention is required. [Originally child, including the physical, cognitive, and social and emotional aspects of development.] The development of Urie's ideas has led us to recognize that we must also target the physical, cognitive, and social and emotional environments where development occurs. The family is the child's primary environment on all these fronts, and the larger society is the family's environment. When the community supports families in their roles and meets their needs, families are better able to meet the developmental needs of their children.

Therefore it seems very clear that the most effective strategies to prevent low-level functioning among poor children are through family support. Since not all families face the same difficulties, they will not need the same types of support. Some may need little more than child care services so they can maintain a decent standard of living. Others may need to be taught baby care and practical information about how children grow and learn. Some will need homes, jobs, and medical services. It is likely that many families will need some combination of supports rather than one, such as preschool for their children. And some will require services only until they can get on their feet, while others will need continuous assistance in one form or another over time.

The wave of the future may well be a variety of available services which families can choose according to their actual needs. A model of this approach was the Child and Family Resource Program (CFRP) which offered a number of services from the prenatal period through the time the child was 8 years old. The backbone of the program was home visitors or "family advocates" who worked to establish a close, trusting relationship with each family and also served as resource persons, advising families of services

available to them from the CFRP and from the larger community. Many of these services were based on the premise that children's development cannot be optimal in the presence of serious, unresolved family problems. Thus, CFRPs involved parents as fully as possible in all decisions that affected their children and also provided certain services for the parents themselves. The accomplishments of these centers so pleased government accountants, a group notoriously hard-headed when it comes to accountability, that a similar model will soon appear nationwide under the name "Comprehensive Child Development Centers."

Another national effort serve young, at-risk children and to ease the problems of their families comes from the amendments to the Education of the Handicapped Act, or PL 99-457. Passed in 1986, the law is being phased in to provide coordinated services to handicapped or at-risk infants and preschoolers. As proof that science does influence social policy in a meaningful way, the amendments embody much of what has been learned from our years of research on early intervention. First, by extending the mandate of appropriate educational services for school-age children to cover the years before school, there is respect for that change as the child grows, and changes will certainly be more effective than efforts to treat the child at one point in time. The services provided are not limited to education, but also cover health and social needs, a broad intervention that holds promise of enhancing social competence in children who may be weak in one or more of these areas.

Like the original act, the amendments also recognize that parents have a profound influence on their children and must be an integral part of the intervention process. Thus, parents are part of a multidisciplinary team that plans and evaluates each child's program. The 1986 rules also recognize that strong families are in the best position to strengthen their children's course of development. The law stipulates an Individualized Family Service Plan in which a case manager is assigned to each family to assess their needs and help them access whatever services they may require. When fully implemented, this law should do much to improve the adaptation of families with handicapped children, and to assure the early identification and long-term treatment of children who are retarded or have significant risk of functioning at a low level.

Another promising development that is not limited to handicapped children is the Parents as Teachers (PAT) program, now available to all families in the state of Missouri. The program provides information and guidance to parents of children between birth and at least 3 years of age. There are also developmental screenings for early identification of problems, home visits to individualize the program, and a variety of other services. The PAT has recently been adapted to accommodate parents of children who are retarded or have other special needs. The benefits of PAT are extended

through the preschool and school-age years in a number of Missouri communities that operate 21st Century Schools. Here, child care and referrals to other means of family support are offered through neighborhood schools. The number of states that are adopting the PAT and the School of the 21st Century suggest a new national trend of parent education and support that has the potential to benefit children of all socio-economic and IQ levels.

The types of intervention services I have talked about today show that we now have some knowledge and are gaining the commitment to alleviate the problems associated with mild mental retardation. Of course, it would be more exciting to point to new methods that can cure retardation, but our knowledge base does not support expectations that changes in societal practices will lead to drastic changes in intelligence. We have also learned that we need not penalize people for being poor by raising their children for them, by abandoning them with the assumption of their probable inherent inferiority, or by recommending an identical regimen to improve their children's collective intelligence. But we do have reason to believe that several kinds of intervention can raise functional levels of intelligence for persons whose measured IQ is commonly low. There is further evidence that a thoughtful coordination of these various interventions could help many children and their families to adapt better to society and to achieve a better quality of daily existence. In my opinion, this is a worthwhile and achievable goal of early intervention efforts.

Summit Panel III

PREVENTING THE "NEW MORBIDITY": COOPERATIVE MULTI-AGENCY APPROACHES AND OPTIONS

February 6, 1991

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THE ROLE OF DEVELOPMENTAL DISABILITIES COUNCILS AND AGENCIES IN PLANNING FOR THE PREVENTION OF MENTAL RETARDATION AND RELATED DISABILITIES

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Prevention is one of the longest-standing goals in the field of developmental disabilities. Historically, prevention has been mentioned as a goal for hundreds of years.

Prevention as a goal was given particular emphasis during the so-called "genetic scare" or "social Darwinism" era, during the late 1800s and early 1900s. During this era, we were urged by leading professionals to use "a strong ax of prevention" and, failing that, to separate people with mental retardation into large institutions so that they would not spread so-called "mental deficiency" in the general population. Within these institutions, people were again segregated by gender so that they would not be able to reproduce. Oliver Wendell Holmes declared "...three generations of idiots is enough."

Early fears about "genetic pollution" or "the spread of feeblemindedness" were proven unwarranted in the early part of this century. Still, the massive segregation of people with mental retardation continued under what Wolfensberger would later term a "momentum without rationales." This segregation continues to this day.

During the middle part of this century, prevention as a goal received another strong push. Dr. Bob Guthrie's work in identifying the etiology of phenylketonuria, following on Dr. Sabin's successful work on polio, provided impetus to the goal of prevention. During the Kennedy years in particular, we saw the formation of the President's Committee on Mental Retardation and the development of a national plan to "combat mental retardation."

Since this time there has been some progress in developing basic clinical prevention strategies. Most notably, we have recently witnessed the licensure of a vaccine which holds the potential of reducing the occurrence of meningitis in young children. However, there have been no breakthroughs of the magnitude once expected, when the "cure" of mental retardation was the goal.

Programs funded by the Administration on Developmental Disabilities have, of course, been involved in prevention activities for many years. Our Florida Developmental Disabilities Council is receiving an award at this very conference for its work in this area. In Iowa, our Governor's Planning Council for Developmental Disabilities was instrumental in developing and advocating for the passage of a Senate Joint Resolution regarding the prevention of disabilities. Our University Affiliated Programs have been for twenty years in the forefront of training and research involving the prevention of disabilities. In a broader context, most of our advocacy efforts have been directed to ensuring that people with developmental disabilities are not given further disabilities through program models which promote dependence, idleness, isolation, and segregation. Rather, our goals for the entire program have become independence, productivity, and integration.

There are two areas of concern when we discuss the prevention of mental retardation. The first of these revolves around the fundamental question, "What is so troubling about people with mental retardation that we must seek to prevent them?" In our zeal to advance the prevention agenda, we must be careful to test our basic assumptions. In an era in which we are seeing people with mental retardation living in their own homes, holding down jobs, marrying, and contributing to their communities, we need to reconsider our objectives. Today, the most universal "tragedy" experienced by people with mental retardation and their families is not so much the existence of an extra chromosome or a troubling IQ score, but the continuing exclusion and prejudice they face when attempting to get on with life, to be valued in their communities, and to participate in everyday activities.

Another area of concern involves the almost fundamentally contradictory message we give to the public when we ask the public to accept, value, and accommodate people with disabilities, while in the next breath we call for strong prevention measures. Is the public only supposed to accept, value, and accommodate these people until we can figure out some clever way to be rid of "them"?

What, then, can be a sensitive approach in this area? How can we lessen the functional impact of disabilities without ruining people's images or giving the public the wrong idea? First of all, I think we can all agree that in spite of the above concerns, nobody in this room wishes to leave this session and be struck by a car. Similarly, none of us wishes to see a child fall through a hole in the ice on a pond and become seriously impaired. Obviously, prevention in this sense has a place. Thus, we should do everything we can in the areas of accident prevention, such as using seat belts, promoting home safety, and the like.

In a similar manner, most of us would argue strongly that if an individual does experience an impairment, the individual should receive rapid and intensive attention in order to lessen the impact of the impairment to the maximum extent possible. Thus, we should provide early and intensive intervention to people who experience disabilities, and we should continue this assistance for as long as necessary.

Third, none of us wants to see people experience disease or sickness that results in impairment. Thus, we should encourage healthy lifestyles, personal attention to unsafe behaviors and the like, while providing quality services to people in need. In this area I believe we should provide support and encouragement to our often beleaguered public health programs.

Finally, we need to make sure that the services we provide, the messages we send, and ultimately the way that we think about and portray people with disabilities do not act as further impairments to the ability of people to function effectively in society. This is the one prevention activity we can all engage in and be successful in immediately. I urge you all to join us in this effort. Thank you.

PREVENTION INITIATIVES OF THE ADMINISTRATION FOR CHILDREN, YOUTH AND FAMILIES TO ADDRESS THE NEEDS OF SOCIO-ECONOMICALLY DISADVANTAGED MOTHERS AND CHILDREN

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A variety of programs and activities of the Administration for Children, Youth and Families (ACYF) are focused on preventive intervention efforts to enhance the lives of socio-economically disadvantaged children and families. Family members served by programs administered by ACYF's Head Start Bureau, Children's Bureau, Family and Youth Services Bureau, and the National Center on Child Abuse and Neglect are at risk of developmental delay, child maltreatment, family breakup, school dropout, substance abuse, unemployment, homelessness, and other negative social outcomes. The primary goals of ACYF programs are to reduce these risks and to improve the quality of life for vulnerable, high-risk populations.

While these programs often provide direct services to children with mental retardation and their families--serving children with mental retardation in Head Start programs, for example--many also work in secondary ways to prevent mental retardation and related disabilities and to ameliorate their effects. Following are descriptions of some of these efforts.

HEAD START BUREAU

Project Head Start

Head Start, now concluding its 25th year, is a comprehensive child development program currently serving 550,000 low-income preschool children and their families in 2,000 communities across the country. A minimum of 10 percent of enrollment opportunities in each state must be made available to children with disabilities, including mental retardation. Head Start has surpassed this requirement in each of the last 17 years; currently, 13 percent of the enrollment is comprised of children with disabilities.

Head Start's four program components emphasize cognitive and language development, socio-emotional development, physical and mental health, nutrition, social services and parent involvement. Together, these components play an important part in the prevention and amelioration of mental retardation and other developmental delays among Head Start children.

- As part of the program's education component which is designed to foster children's development, self-esteem and cognitive growth, developmental assessment information is routinely gathered by Head Start staff and augmented by parents' observations. When screenings or referrals indicate that a child may have a disability, evaluations are conducted. If a disability is present, Individualized Education Programs (IEPs) are written and services provided or accessed in an effort to intervene early enough to reduce the effect, overcome the problem, and prevent secondary disabilities. In order to provide guidance for the education coordinator and other staff on working with children with disabilities, Head Start has developed performance standards for Services for Children with Disabilities, which will be published in the Federal Register as a final regulation later this year.

- Through the health component, children receive physical examinations, including vision, hearing, and blood tests; referrals for remedial action are made if needed. Technical assistance, training, and consultation in the areas of medical and mental health are provided through an agreement between Head Start and the U.S. Public Health Service. Mental health services in Head Start aim to reduce the often high levels of stress which negatively affect children and families in low socioeconomic groups. One example of Head Start's efforts in this area is the publication and dissemination of a preventive mental health booklet for preschoolers, entitled As I Am. Another is a mental health curriculum focused on prevention which was recently developed for Head Start by Georgetown University.

- Through the parent involvement component, parents receive information on child development, training to enhance their parenting skills, practice in making decisions, and experience in

working and playing with young children. They also learn how to promote their children's healthy development, both while their children are in Head Start and after they move into the school system. As a result, parents gain self-esteem and self-confidence and become advocates for their children--essential qualities if they are to help their children fulfill their maximum potential. Moreover, as parents learn appropriate childrearing practices and have realistic expectations for their children's development, the likelihood that the children may develop emotional problems or be turned away from learning is reduced.

Head Start also encourages career development and provides training and opportunities for parents to move progressively from volunteers to paid aides, teachers, component coordinators and program directors. One third of the staff currently employed in Head Start programs started in the program as volunteers. As family income and parents' knowledge of child development and behavior increase, and as improved nutrition and access to health care are achieved, the risk of developmental delay among children is reduced.

- The social services component helps families gain access to other community resources for which they may be eligible. Social service coordinators also help parents access the Supplemental Security Income (SSI) and Early and Periodic Screening, Diagnosis and Treatment (EPSDT) systems, which can lead to the early identification and remediation of problems and disabilities.

To help component coordinators and other staff address the specific needs of children with disabilities, Head Start has funded Resource Access Projects (RAPs) in the 10 Regions to provide training and technical assistance (T/TA) to Head Start programs. Other specialized T/TA providers work with Head Start's Migrant and American Indian programs. In addition to providing direct assistance, the T/TA providers locate or develop needed resource materials for distribution to programs. For example, information on Fetal Alcohol Syndrome was developed and disseminated by the T/TA provider serving American Indian programs, and a training package on Social Integration

of Children with Disabilities was developed, and is currently being field-tested by the RAPs.

Head Start also prepares and disseminates information on resources, research and in-service training to further assist staff in their efforts to serve Head Start children with disabilities and their families. Recognizing the diversity of cultures and ethnic groups reflected in Head Start programs, Head Start also provides information on cultural differences which affect how groups view disabilities and intervention efforts so that staff members will be informed and realistic in their planning of services.

Parent Child Centers

The Head Start program includes 37 Parent and Child Centers (PCCs) serving 4,500 children and families in 28 states. In FY 1991, the PCC program will be expanded significantly to reach an additional 4,900 children and families in all remaining states. PCCs are comprehensive child development and family support programs established to serve children from birth to age three, their families, and pregnant women. Program approaches are aimed at preventing the development of health, intellectual, social and emotional deficits in infants and toddlers, while maximizing each child's inherent talents. Services to pregnant women include counseling and comprehensive prenatal care, as well as the prevention of nutrition-related deficits.

Research and Demonstration

Head Start provides financial assistance though grants or contracts for research, demonstration, or pilot projects designed to assist in the development of new approaches or methods that will aid in preventing and overcoming special problems. Over the past few years, for example, four Head Start programs have received grants to develop services targeting HIV-infected children and their families. Several other programs were awarded grants to address ways of preventing or reducing problems of substance abuse among Head Start parents. Head Start is also collaborating with the Office of Substance Abuse Prevention to make the most current information and resources available to Head Start programs.

In FY 1990, Head Start awarded grants to 13 Head Start agencies to develop Family Service Centers, which are developing approaches to support Head Start families in attaining self-sufficiency. Through collaborative efforts with other community programs, the centers will focus efforts on preventing and reducing substance abuse, improving the literacy skills of parents, and increasing the employability of parents.

Comprehensive Child Development Program

Under the Comprehensive Child Development Act, 24 demonstration projects were funded to provide intensive, comprehensive, integrated, and continuous support services to low-income families with young children. Among the array of services that families receive are early intervention for children with or at risk of developmental delay; prenatal care, including nutrition services, for pregnant women; and education in infant and toddler development.

CHILDREN'S BUREAU

Among programs administered by the Children's Bureau that affect children with mental retardation, their families, and other caregivers are projects that offer respite care for families who adopt children with special needs, respite care and temporary crisis nurseries for children with disabilities, and specialized family foster care for older children with mental, emotional, or physical disabilities.

Under the Abandoned Infants Assistance Act of 1988, the Children's Bureau has funded 24 demonstration projects to prevent the abandonment of infants born to mothers with Human Immunodeficiency Virus (HIV) infection, Acquired Immune Deficiency Syndrome (AIDS), and other medical problems. In addition to addressing the special needs of the babies, who are at high risk of developmental delay and other negative outcomes, the projects are developing ways to identify mothers at risk of abandoning their children and to provide services to help them bond with their infants and prepare to care for them at home. The projects are also preparing infants who cannot reside with their natural families for placement in family foster home, and recruiting and training care-givers.

Additionally, the Children's Bureau is planning to support demonstration projects in FY 1991 for the development or replication of a variety of affordable respite care models for the adoptive parents of children with special needs, especially the parents of medically fragile or severely physically or emotionally disabled children. These projects will be designed to provide needed support to these parents during periods of emergency as well as respite from the daily demands of caring for a special needs child.

The Temporary Child Care/Crisis Nurseries Program authorizes grants, through the states, for the development of temporary non-medical child care or respite care services for children with disabilities and children with chronic or terminal illnesses, including children with AIDS or AIDS-related conditions. These programs are designed to provide families or primary care-givers with periods of temporary relief from the

demands of child care to prevent severe family stress. Services may be available on a 24-hour basis, and can include referrals to counseling/therapy, medical services and other needed assistance. A survey of a sample of funded crisis nursery programs, conducted in September 1990, found that 19 percent of the children served were mentally retarded; 19 percent had development delays; and, 12 percent were at risk of developmental delays.

Support is also being provided for the development of specialized foster homes for children ages 11 through 18 with physical, mental, or emotional disabilities. An increasing number of older children are entering the foster care system, many of whom enter and remain in care due to a variety of behavioral difficulties resulting from physical, mental and/or emotional problems. While specialized foster care has been found to be effective in addressing the needs of these children and in preventing unnecessary institutionalization, the current supply of such homes is insufficient to meet the demand. These demonstrations, which include the provision of specialized training, support services, and other needed assistance are designed to assist in filling this service void.

NATIONAL CENTER ON CHILD ABUSE AND NEGLECT

Several programs supported over the last five years by the National Center on Child Abuse and Neglect (NCCAN) to prevent child maltreatment also are particularly relevant to the prevention or amelioration of mental retardation. Between 1986 and 1989, NCCAN-funded projects were designed to reduce the risk of developmental delay among infants of chemically dependent mothers and to improve the childrearing skills of teen parents. More recently, NCCAN awarded grants for model comprehensive community-based prevention programs that include prenatal health care, parenting education and support programs for new parents, and support programs such as respite care and crisis nurseries for parents under stress. NCCAN also funds a clearinghouse to assist agencies that work with another high-risk group of children--disabled infants with life-threatening conditions. The National Information Clearinghouse on Disabled Infants with Life-Threatening Conditions disseminates information on treatment procedures, services and resources available to infants and their families, including social and parent support services.

Among the research studies supported by NCCAN are two that have examined possible links between child maltreatment and mental retardation. Researchers at Cornell University and the University of Georgia suggest that child maltreatment may adversely affect the life chances of any child, particularly children with mental retardation who are at risk for academic failure and social/emotional dysfunction. Prevention programs targeted to child maltreatment may be of help in reducing such risk.

Finally, ACYF recognizes that coordination with other agencies concerned with the prevention and amelioration of disabilities is essential for successful intervention. Accordingly, ACYF is a member of the Federal Interagency Coordinating Council (FICC), the Federal-level counterpart of the State Interagency Coordinating Councils required under the Individuals with Disabilities Act (IDA). A subcommittee of the FICC is currently developing an interagency agreement between the Department of Health and Human Services and the Department of Education, involving ACYF, the Administration for Developmental Disabilities, the Maternal and Child Health Bureau, the Social Security Administration, the National Institute of Mental Health, and the Office of Special Education Programs. Under this agreement, the agencies will work together to identify infants and children with disabilities who are in need of services, and will jointly coordinate and provide services and referrals for children and families.

As the above descriptions indicate, ACYF's efforts related to mental retardation cut across a variety of population groups--including infants, preschool children, children with special needs who are placed in adoptive homes, and older children in foster care--and embody a variety of different approaches for dealing with the problem such as direct services, referrals, educational activities, counseling, research, and demonstration efforts. Many of these activities are nationwide in scope, and in the aggregate, impact upon the lives of many thousands of people. Singly and in combination, we believe these efforts are making a significant contribution to helping prevent mental retardation and other related conditions and to alleviating the problems of children with disabilities and their families.

SUPPORT SERVICES OF THE MATERNAL AND CHILD HEALTH BUREAU IN PLANNING TO PREVENT MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES IN CHILDREN

by Vince L. Hutchins, M.D.
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The Maternal and Child Health Program (MCH) is pleased to be a member of this panel on prevention of the New Morbidity. The setting itself, appearing with representatives of sister agencies, is a testament to the collaborative approach that is necessary and occurring in the field of prevention of mental retardation and related disabilities. This theme of prevention is continued in tomorrow morning's panel on improving the health status of children with its emphasis on services and training. Participants from the agencies and their programs in both panels are in a sense interchangeable. For it is collaboration among these and other agencies and organizations in the triad of research, training, and services that has contributed to the advances in prevention of the New Morbidity over the latter half of this century.

This afternoon I will discuss the newly revised Title V, the legislative basis of the Maternal and Child Health Program, as it pertains to the theme of this conference.

While preparing for this presentation, I could not help but sense the historical continuities implicit in the conference materials:

- MCH is proud to have been among the supporters of Dr. Robert Haggerty and his colleagues in Rochester. These community studies led to the landmark 1975 publication that introduced us to the term and concept of the New Morbidity.

- The Federal Maternal and Child Health Bureau, while only recently created, is an update of two antecedent organizations--the Children's Bureau and the Maternal and Child Health Services. An early Children's Bureau study, here in the District, focused first on the problem of clearly defining

mental retardation and distinguishing it as a problem separate from illiteracy and poverty, and secondly focused on the kinds of services these children needed. Subsequently, selected highlights of the MCH program include:

- Study in the 1920s of work histories of minors who had been pupils in special classes for the retarded.

- In the 1950s, development of community health and welfare services for young mentally retarded children including pediatric-directed child development and evaluation clinics.

- The 1962 report of PCMR's predecessor, the President's Panel on Mental Retardation, resulted in four major MCH changes:

  1) The establishment of maternity and infant care projects to improve prenatal and infant care--primary prevention.

  2) The expansion of newborn screening--secondary prevention.

  3) Stressing the importance of providing care of secondary handicaps in the then Crippled Children's Service--tertiary prevention.

  4) The birth of the University Affiliated Facilities (UAFs) now grown up to be UAPs, the training authority for providers for this population.

In the past few months, two events have occurred that bring this brief review of program development up to date:

- The last Congress directed MCHB to fund two new health training components in UAPs--one in Appalachia, one in the

West--both to have an emphasis on prevention and rural populations.

- Two days ago, the President in his budget message announced a new targeted infant mortality initiative that will be directed to 10 communities in the nation with exceptionally high infant mortality rates. "Developing a strong (local) MCH system," "interventions addressing unhealthy behaviors," "aggressive program of outreach, public information" and "case management" are among the phrases used.

A few comments about recent legislative changes in Title V. In this century, numerous efforts at all levels of government have succeeded in improving maternal and child health. Advocates for children, including professional workers in the field, parents, private citizens, legislators, professional organizations, women's groups, and voluntary agencies, have been components of the constituency that has stimulated and monitored these efforts over the years.

A major philosophical change occurred with passage of the Omnibus Budget Reconciliation Act of 1981 which established the Maternal and Child Health (MCH) Service Block Grant to replace the previous formula grant program. The relationship with the states which had evolved from a Federal-state partnership to a state-Federal partnership was codified in the 1981 amendments. Several prior separate programs were now included in the Block. The states were given more leeway to utilize the funds to establish programs to meet their populations needs as they assessed them. New language included a restatement of the purposes, an emphasis on coordination with other agencies serving mothers and children, a prohibition on charges made for service to low-income mothers and children, and a requirement that the states planned use of the funds be made available for public comment. "Assure access to quality...services" was added to the purposes.

A clarification of the state-Federal partnership occurred with the enactment of the Omnibus Budget Reconciliation Act of 1989 (OBRA '89). The amendments created a new framework for action on maternal and child health for the 1990s. They explicitly link Title V program purposes to the Health Objectives for the Nation for the Year 2000.

Other changes include:

- "Improve the health of all mothers and children," as a new goal.

- Expand and make structural changes in the Title V Maternal and Child Health Block Grant Program to improve planning and accountability in the program and to complement Medicaid reforms for pregnant women and children.

- Support special new activities such as common application or eligibility to improve access to "maternal and child assistance" programs.

  (MCH assistance program =
  - MCHS Block Grant (Title V)
  - Title XIX Medicaid
  - Migrant and community health centers
  - Grants for the Homeless
  - Women, Infants and Children (WIC)
  - Head Start

- New state application for Block Grant funds.

- New annual reporting by states.

- Facilitate development of family-centered, community-based systems of services for children with special health needs and their families. This language is repeated in the Year 2000 Objectives and provides the opportunity and challenge to develop these systems at the community level across the domains of services that those children and families need.

- New state application for Block Grant funds. This application must include:

  - Statewide needs assessment.

  - Plan for meeting identified needs.

  - Assurance of at least 30 percent for preventive and primary care services.

- Assurance of at least 30 percent for CSHN services.

- Assurance that FY 1989 level of state effort will be maintained.

- Provision for Title V agency participation in interagency coordination with related programs.

- Provision for identification of, and application assistance for, Medicaid-eligible pregnant women and infants.

These provisions reflect work remaining to be done by Federal and state authorities in developing effective statewide systems of comprehensive, community-based, family-centered, continuous care and in using resources more efficiently through effective coordination of MCH Block Grant activities with those of other major "maternal and child health assistance programs."

The provisions also represent opportunities for program folk, advocates and families to become involved in the process of program development at the community and state levels.

The OBRA '89 amendments to Title V are another step in the evolution of a partnership for the health of mothers and children. The law now contains a number of expanded and new provisions to address the unmet needs of children and families in contemporary America, including the reduction of infant mortality and low-birth weight; the reduction of children injuries, abuse, disease, and disability; and the reduction of adolescent pregnancy, AIDS, and substance abuse--all contributors to the New Morbidity.

It is particularly fitting that the first Federal grant-in-aid provision for the health and welfare of the individual would be concerned with children. Through nearly a century of legislation, this important focus has been modified and improved through amendment. Our future has been and will be dependent upon it.

SOCIAL SECURITY INITIATIVES THAT IMPACT THE LIVES OF FAMILIES AT RISK AND REDUCE CHILDREN'S MORBIDITY

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Good afternoon. It is certainly a pleasure to be here today to participate in this very worthwhile summit, and to discuss with you an issue so critical to the life and health of American children.

As Commissioner of Social Security, I am particularly happy to join you in this effort today because I believe social security has a very definite and important role to play in reaching out to the children in our society--those children, in particular, who are in desperate need and are without even the minimum, basic necessities they need to get their young lives off to a good and healthy start.

A lot of people think the agency I manage is only a retirement program and that its sole beneficiary population is our nation's senior citizens. But as most of you here today know, that is not true. Social security serves men, women, and children from all age groups, and its service extends to everyone from tiny babies to centenarians.

This afternoon, I welcome the opportunity to join forces with those of you who have chosen to give of yourselves for children in need. I want to share with you a little bit about what the Social Security Administration (SSA) can do, and is doing, for children with disabilities and their families, and how our program can work in concert with your efforts to try to minimize the socioeconomic factors that often tragically prevent a child from getting that happy, healthy start in life.

This conference offers us a great opportunity. It gives us the occasion to pool our energies, our resources and our varied areas of expertise to ensure that our society's most vulnerable citizens--our children--are not denied the most precious opportunity of all, the chance to begin their lives free of the kind of want and the kind of economic deprivation that might rob them of the joys of childhood and later, of a healthy, productive life.

As physicians, advocates, social workers, academics, parents, and public servants, we are each all too familiar with the pattern of human tragedy we have gathered to discuss: young women not receiving adequate prenatal care; young, pregnant women who are malnourished; babies who are born at low birth weights with a great likelihood of some degree of mental retardation; babies who are born to mothers addicted to crack cocaine, or who are exposed to such high levels of alcohol before birth that they are born intoxicated and doomed to spend the rest of their lives with birth defects that may result in mental retardation; babies going home to poverty and a continued lack of adequate medical care; babies who, because of this poverty, will be denied the enriching and stimulating experiences that are so vital to the learning process; and finally, an increasing population of adults with retardation, adults who have great difficulty functioning in society.

We've all heard the numbers, too. There are six million individuals in this country with mental retardation. Of these six million, four million are caused, at least in part, by socioeconomic factors. In other words, factors that can and should be eliminated, and conditions that can and must be prevented.

Two hundred seventy thousand babies are born each year with low birth weights. Five thousand babies are born each year with fetal alcohol syndrome. Sixteen million youth are without health insurance--a 13 percent increase in the last five years. One in ten children under the age of four have not seen a doctor in the last year.

Considering these statistics, it is no wonder that so many families are feeling angry, frustrated, and afraid. It is no wonder that many feel as though they have no real options available to them to help break this vicious cycle.

One year ago, I met with Dr. Sambhu Banik and some of his staff to hear concerns about at-risk populations. We shared our concerns about those children who lag behind mentally or physically because of inadequate or nonexistent pre- or postnatal care. We discussed ways in which the social security administration might help in reaching and meeting the needs of these at-risk populations.

Well, I am happy to say that out of that informal dialogue, came Social Security's cosponsorship of this summit. And I would like to thank and commend Dr. Banik (PCMR's Executive Director) and Dr. Albert Anderson (PCMR's Chairman) for their efforts, along with so many others, in putting together this very valuable and needed conference together.

At the Social Security Administration, I think of the work we do in a two fold sense. First, we have a responsibility to implement the programs that administrations propose and congresses create, a responsibility to carry out our statutory duty. But second, and more important, we have a moral responsibility to look beyond the letter of the law, to look at the full, comprehensive needs of the people we serve and those we seek to serve, and to determine how best, within our authority and within our capability, we can meet those needs. I want to share with you today some of the steps we are taking to fulfill our public responsibilities in both senses, and specifically as they relate to the at-risk populations we are discussing here today.

Currently, through our Supplemental Security Income (SSI) program, the Social Security Administration provides monthly cash assistance totaling about $121 million to some 312,000 children with disabilities and their families who have limited income and resources. Of these 312,000 children, more than 111,000 are children with mental retardation.

While dollars cannot make a child's disability go away and while SSI will not entirely eliminate financial difficulties, monthly benefits from this program can make a difference by providing basic necessities for a child with disabilities and his or her family. Eligibility in the program also may open the door for Medicaid eligibility and other state and Federal services.

For those enrolled and receiving benefits, the SSI program has helped. But I must say candidly that SSI is not yet an unqualified success. Not when there are still people in cities, towns, and communities across this nation who need its help and are entitled to it, but are not receiving it. Not when there are children whose lives could be set on a different course if they were receiving these benefits.

Although it is difficult to accurately measure the exact number of potential SSI beneficiaries who are not presently on our rolls, but who could and should be, we do know that there are men, women, and children who could and should be receiving these benefits, but who, for any number of reasons, are not.

To the extent that these people exist, with chronic needs unmet, we cannot be satisfied that we have succeeded in administering SSI. This is an endeavor in which we cannot tolerate failure, failure that is measured in terms of human lives.

We, at the Social Security Administration, are searching for every possible way to more effectively and fairly administer this program and bring it to all of our nation's most vulnerable citizens who need the lifeline it can provide.

For example, since I became Commissioner, I have made SSI outreach a major priority at SSA. This means going into cities, towns, and communities across the land and bringing word of the program to the more at-risk and hard-to-reach populations that may not know of it. It often means finding people that members of these at-risk populations will trust to explain the program to them, to alleviate their fears or misconceptions about the program, and to help them through the application process.

The centerpiece of our SSI outreach efforts is a grant program designed to test innovative approaches to removing the barriers that are preventing people from learning about and applying for benefits that could make such a difference in their lives. Last October, we divided $3 million in Congressionally-appropriated funds among 25 organizations throughout the country in the form of grants and cooperative agreements. And this year we will have an additional six million in outreach demonstration funds.

These organizations will try a variety of means, in varied geographic locations, to reach different types of potential beneficiaries with news of the SSI program. And some of the programs are designed specifically to reach the low-income families who have children with disabilities.

- For example, the Mental Health Law Project of Washington, D.C. is conducting outreach to children with disabilities in Maryland, North Carolina, and Texas.

- The National Parent Network on Disabilities, based in Alexandria, Virginia, is targeting disabled youth in Kansas City, Philadelphia, and Missouri, using a parent-helping-parent approach, to do outreach, case management, and follow-up.

- In Jersey City, New Jersey, St. Joseph's School for the Blind is using its SSA grant to establish a statewide outreach strategy to identify blind children and young adults who may be eligible for SSI.

- Another organization, AIDS Project Los Angeles, is targeting all segments of the HIV-positive population, including intravenous drug users and their children.

I am excited about these and other demonstration projects that SSA is funding because I know they will yield more effective ways of reaching the children with

disabilities and their families that we have found so difficult to reach in the past. They will be effective because they are utilizing the knowledge, skills, and the contacts of individuals in their own communities to find the best ways to reach potential SSI beneficiaries in those particular communities. What works in one area with one population, will not necessarily work in another area, and these people are in the best position to know what will work best and where.

From these projects, we hope to build a strong, solid foundation for ongoing SSI outreach all over the country. But our efforts do not stop there. We are disseminating the SSI message through new brochures, posters, mass transit cards, and most important, through word-of-mouth via community activists and concerned organizations, show posters, and/or SSI booklet designed for children.

On another front, we are now on the threshold of publishing new regulations that will make far-reaching changes in the way we evaluate disability in children who apply for these benefits.

Within a few days, Secretary Sullivan will announce the publication of these rules, which represent our very best, most thorough and comprehensive effort to bring SSA's evaluation of childhood disability cases into line with state-of-the-art practice in pediatric and adolescent medicine.

These new regulations are the result of the Supreme Court's decision in Sullivan vs. Zebley, in which the court held that our regulations were too narrow, that they too strictly interpreted the standard of eligibility provided in the law for determining whether children are disabled.

Under the Social Security Act, we are required to find a child eligible for supplemental security income benefits if that child has an impairment that is comparable in severity to one that would disable an adult. Prior to the Zebley decision, SSA made this determination by comparing a child's impairment with our regulatory listings of impairments.

If a child's impairment was not on the list or was not the same as-or equivalent in severity to one on the list, SSA determined that the degree of the child's disability was not severe enough to make him or her eligible for the SSI program.

Now, the problem with this approach was that it did not take into consideration additional factors like the ability to perform "vocational" tasks, which is a factor considered when evaluating disabilities in adults.

Of course, the reason SSA did not consider this additional factor in children was because vocational analysis is inherently inapplicable to children. So from 1976 until recently, the agency used the narrow means at its disposal at the time to determine disability in children. But, as the court has ruled, that was not good enough and excluded many children--specifically, children with disabilities like Down's Syndrome, Muscular Dystrophy, Spina Bifida, Aids, Cystic Fibrosis, and other chronic illnesses.

And so, in response to the court's findings and its mention of the possible use of a functional analysis to measure a child's ability to perform age-appropriate daily activities in lieu of the vocational analysis, we began immediately to solicit the advice and services of leading experts in various pediatric subspecialties, child psychology, special education, rehabilitation, and in the evaluation and treatment of disability in children.

The new regulations that Secretary Sullivan will announce imminently, represent a distillation and culmination of advice and input from these and other experts. And we are confident that the new rules, in conjunction with those other regulations published in December, offer a fair and contemporary means for determining disability in children.

This, in turn, should mean that children with the types of disabilities that we were previously unable to assess properly will, upon initial application or upon reexamination of their claims, be determined eligible for SSI benefits. And to the extent possible, this will mean retroactive relief for many children previously denied benefits.

The creation and implementation of the new regulations is one major way in which the Social Security Administration is vigorously working to see that the SSI program reaches the entire population of children with disabilities that it was intended to reach. But we know that there is much more that we can and must do, and so we have other major efforts underway.

SSA is working closely with the American Academy of Pediatrics to increase pediatrician involvement in our disability review process. We are engaged in discussions with a number of other organizations to identify ways to work with more health professionals to bolster SSA's disability program. And we are working with Dr. Mason, the Public Health Service (PHS), the Surgeon General, and the Bureau of Maternal and Child Health, to better our handling of children with special health care needs.

We are developing our relationships with people who share our desire to see needy children with disabilities get the assistance they so desperately need because we are sure of one thing: government alone cannot get the job done, and no single agency alone can get the job done. SSA alone, through its SSI program, can help alleviate some

of the socioeconomic conditions that contribute to mental retardation, but our program and our efforts alone cannot impact significantly on the ratios as they presently exist. But with the new opportunities for interagency and extra-agency cooperation, we can make a significant contribution.

I do not, however, want to minimize the difficulties involved in coming to terms with this problem of a growing population in our society of children and adults with mental retardation. As we all know, the social factors that have contributed to this problem are very deeply rooted and difficult to reverse. But what I do want to say is that SSA is committed to working alongside its sister agencies, and working alongside interested individuals and organizations to address this problem effectively.

Our long-term planning must include interagency and interorganizational efforts in order to meet the challenges ahead of us. Each of us can do our part to address one aspect of a person's needs, but we do not do our job properly if we don't view that person as a whole and look at the entire, comprehensive panorama of needs they have which fall within the government purview. We must work together in order to help the whole person, not just selective parts. This new spirit of cooperation can bring us new hope for making real headway toward conquering America's social problems, no matter how steep and challenging the obstacles ahead might be.

I see these obstacles as somewhat like the hurdles in a steeplechase. When you ride up to them, if you throw your heart over, if you throw your full commitment and intentions over, the horse will go along too. And if those of us here today throw our best efforts and our cooperation over, we will indeed be able to clear the hurdles and go beyond our statutory responsibilities to fulfill our greater responsibility of meeting the comprehensive needs of the people we exist to serve. Thank you.

REHABILITATION SERVICES ADMINISTRATION OPTIONS FOR INTERAGENCY INITIATIVES IN PREVENTION AND REHABILITATION

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The Rehabilitation Services Administration (RSA), a Federal agency which exists within the U.S. Department of Education, was established by the Congress of the United States to administer the authorities of the Rehabilitation Act of 1973 and subsequent amendments through 1986, and the authorities of the Randolph Sheppard Act.

For Federal fiscal year 1990, the program budget for RSA is $1.5 billion. Of this amount, more than ninety percent goes to the state/Federal Vocational Rehabilitation (VR) Program. The Vocational Rehabilitation Program itself is much older than the Rehabilitation Act. This employment-oriented service-delivery program was established in 1920 and has enjoyed a seventy-year successful existence preparing disabled individuals for, and placing them in, competitive employment.

I am sure that everyone here today already knows that the state/Federal VR program is administered as a joint partnership between the Federal and state governments. RSA responsibilities in the partnership are to provide approximately 80 percent of funding for the program, promulgate regulations and policies to give program guidance, assure compliance with Federal statutes in administering the programs, and provide leadership and direction through technical assistance and consultation.

The Federal partner carries out these responsibilities from our central office in Washington, D.C., and with the able assistance from a staff of rehabilitation experts in 10 regional offices throughout the country. Tennessee is served by our Region IV office in Atlanta.

In addition to the state/Federal VR program, RSA administers a number of other programs that provide rehabilitation services and independent living services to Americans with disabilities.

Our supported employment programs were authorized under the 1986 amendments and are designed to provide employment services to the most severely disabled. The focus of these programs is to offer employment opportunities in integrated work settings, with the provision of support systems such as job coaches, until such time as the disabled individual is capable of functioning in the work place without support. Our current funding for supported employment is about $60 million annually, available under Title VI, Part C under formula grants to state VR agencies and under Title III, funding is available to community-based projects.

Title VII of the Rehabilitation Act authorizes RSA to provide independent living services in three categories: Part A, grants to state VR agencies; Part B, funding for centers for independent living; and Part C, independent living programs for the older, blind population. Overall, approximately $67 million annually goes to support the independent living programs. The thrust of these programs is to improve the quality of life for millions of Americans with disabilities through such services as peer counseling, community integration, assistive technology, and many other services designed specifically to elevate or maintain the level of independence of the individual.

In addition to the direct services programs I have already described, RSA also administers vocational rehabilitation programs for disabled Native Americans residing on reservations and for disabled migrant farm workers. These programs focus on meeting the unique vocational needs of the special populations and are administered through the competitive grant process.

RSA is authorized to administer a Client Assistance Program under Title I. This program is designed to provide advocacy for clients and client applicants for vocational rehabilitation services. The program is funded with formula grants to states. At the state level, the chief executive officer (governor) designates the organization to administer the program. RSA provides guidance, monitoring, and technical assistance to the designated organization in each state.

To support all of the programs I have just described to you with trained personnel, the Rehabilitation Act under Title III, authorizes RSA to administer a training program to prepare rehabilitation professionals to provide services in all of the categories of services delivery. Each year we spend $31 million preparing rehabilitation counselors at the bachelors, masters, and doctoral levels, O and M: instructors, interpreters for the deaf, occupational therapists, work evaluators, rehabilitation nurses, rehabilitation psychologists, and many other professional categories to meet the ongoing needs of the field.

What is the future of RSA and the programs we administer? The future is very bright as we approach the 1991 Preauthorization of the Rehabilitation Act. In the many, many public contacts we have made soliciting input on preparation for reauthorization, we have found a tremendous amount of support for both vocational rehabilitation and the independent living programs. While there is a lot of competitive spirit between the two programs, there is also a lot of support for each.

With the passage of the Americans with Disabilities Act (ADA), and more importantly with its implementation in two years, RSA will develop new and strong relations with other Federal agencies such as the Equal Employment Opportunity Commission, the Department of Justice, the Social Security Administration, and the President's Committee on Employment of People with Disabilities. As we meet the new challenges and opportunities created by implementation of ADA, coordination and combined efforts will be required in order to meet the educational needs, technical assistance needs, technology needs, and information needs of consumers, employers, educators, advocates, and private citizens. More and more, we will see a closer working relationship between the state VR agencies and Governor's Committees for Employment of People with Disabilities, and more and more we will see those relationships translating into increased opportunities for people with disabilities.

For all that we have accomplished over the past three decades for our efforts to secure the rights of disabled people as first class citizens, the number one need of this population continues to be employment--meaningful employment. It is estimated that of the 46 million Americans with disabilities, only 30 to 35 percent are engaged in meaningful employment. That figure is not good enough. We must join forces to assure that those disabled Americans who want to work are given the opportunity.

Speaking to the 1990 National Conference of the President's Committee for Employment of People with Disabilities, Patricia Neil said "To work again after a disability is the ultimate affirmation of life." Over 97 percent of the $1.5 billion spent by RSA this year on programs was directed toward employment and an improved quality of life for persons with disabilities. Is our future bright? It is because we are focused on a recognized, desirable outcome--employment.

AMELIORATING THE EFFECTS OF MENTAL RETARDATION AND RELATED DISABILITIES IN AGED ADULTS

by Joyce Berry, Ph.D.
U.S. Commissioner on Aging
U.S. Department of Health and Human Services
Washington, D.C.

Thank you and good afternoon. Let me just say that I appreciate the opportunity to be a part of this meeting, and I want to describe very briefly some of the Administration on Aging's responsibilities under the Older Americans Act.

The older Americans Act is a statute that was enacted 25 years ago which basically set forth fundamental objectives for improving the lives of older people. The Administration on Aging (AOA) is responsible for seeing to it that provisions of the Act are carried out. AoA also shapes national policies affecting implementation of the law. One of the major goals of the legislation is to insure that older people maintain their independence by remaining in the community.

Programs under the Older Americans Act, funded at about a billion dollars a year, operate through a network of about 670 state and area agencies on aging across the country. You have probably heard of the city or county office on aging or the home delivered meals program in your community or the nutrition program for older persons. Those programs are funded under the Older Americans Act with the money allocated through state and are agencies on aging.

We are very concerned about seniors with mental retardation who live in the community. These seniors often require a range of supportive services, including ones that we can provide through the network I just mentioned. We are also very concerned about their caregivers, who are often older people themselves. We know that one of their greatest fears is that after they die, there will be no one to care for their adult children. In fact, it occurred to me on the way over here that a few years ago, a commissioner on aging would not have been a part of this panel because persons with mental retardation had a very limited life expectancy compared to the general population. Due to increased longevity for persons with developmental disabilities to other factors, the field of aging is now very involved in matters relating to persons with mental retardation.

I must give credit to Commissioner McFadden for involving me in these issues, and it has certainly been a pleasure working with her. I mentioned the caregivers of the mentally retarded because it is becoming increasingly common for older parents in their 70s or 80s to be caring for a disabled son or daughter who is 50 or 60 years of age.

So the Older Americans Act programs, offer a wealth of opportunity in terms of making sure that adults with mental retardation and their caregivers remain in the community, which is where they want to be. Less than five percent of older people are, in fact, in institutions. Older people want to stay in the community and seniors with mental retardation are no different in that respect. Their caregivers, however, need support to keep their mentally retarded children outside of institutions. Older adults with mental retardation need a whole range of services. You all know what they are. They need adult day care. They need homemaker, home health aides, home-delivered meals, transportation services and so on. Commissioner King and I have been working together to try to make sure that older people do not flounder about, as he mentioned, when looking for services. We have been trying to work under Secretary Sullivan's leadership to make sure that there are common focal points in the community where older people can go for services.

Commissioner McFadden and I have just recently funded four projects to strengthen assistance to persons with disabilities. Since I am sure she spoke about these projects, I will only refer to them briefly. We have projects in New York, Virginia, Wisconsin, and Mississippi where we are trying to forge linkage between the aging network and the networks serving persons with developmental disabilities in order to enhance supportive services.

This panel could focus on achieving better coordination between the service networks, which is the objective of a number of Memoranda of Understanding (MOU) between AoA and other agencies. For example, Dr. Horn and I signed an MOU focused on increasing exchange of information and contact between the generations. AoA and ACYF have jointly funded projects to involve more older people in Head Start centers and children's programs. Dr. Graves and I recently signed an MOU in which we pledged to work together on issues related to seniors who are disabled. There are a number of efforts that we are making at the Administration on Aging to make sure that we do not forget the needs of the mentally retarded.

Let me just say, in closing, that perhaps the most exciting thing that we are engaged in right now is that the Administration on Aging has launched, under the leadership of the Department, a National Eldercare Campaign. What we want to do is to try to heighten the nation's awareness of the needs of older people at-risk.

In general, I think we do a disservice to older people if we present a picture that most older people are downtrodden, that they are poor and that they need our assistance when, in fact, quite the contrary is the case. Most older people are resourceful, they are active, and they are living meaningful lives in the community.

So AoA has decided to place great emphasis on that smaller but sizeable group of older people who are at-risk which certainly includes the target group that we are concerned about today.

Essentially what we are trying to do through the National Eldercare Campaign is to heighten public awareness of the needs of older persons at-risk and programs available to help them. Commissioner King, for example, has expressed her concern about the many seniors who still do not know about SSI, and we have been trying to work together on improving outreach to enroll seniors.

The other part of the National Eldercare Campaign relates to coalition building as a key element in our approach to solving problems. Commissioner King also touched on the fact that the solution to problems can not rest completely with government at the Federal, state, or local level. What we hope to do in coalition building is to ask communities to work with organizations, and entities that have traditionally not been involved with aging issues, such as civic and fraternal organizations, the academic community, and business and labor. We will provide some support to selected communities that want to work with us, on a demonstration basis, to show how non-traditional approaches to providing services to older persons at-risk can, it fact, succeed.

A third component of the campaign relates to trying to get new partners. We have been meeting with the U.S. Chamber of Commerce, the National Alliance of Business, the National Association of Manufacturers, the Red Cross, Goodwill Industries and many other organizations that have not traditionally been involved in aging. We are asking them to integrate aging into their agendas and, where possible, to focus assistance efforts on older persons at-risk of losing their independence.

So, in concluding my comments, I would like to urge your involvement in this new National Eldercare Campaign. I would be happy to provide you with more information about it as it develops. The campaign is, primarily, an advocacy effort. I think that persons with mental retardation are a very important target group in the National Eldercare Campaign, and I welcome your support and participation. Thank you.

NIDRR: SCOPE OF OPPORTUNITY FOR INTERAGENCY COLLABORATION AND RESEARCH IN MENTAL RETARDATION

by William Graves, Ph.D.
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National Institute on Disability and Rehabilitation Research
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Richard Rodgers collaborated with Lorenzo Hart on The Girl Friend and Pal Joey and with Oscar Hammerstein II on Oklahoma, The King and I, and The Sound of Music. Dick Rodgers' collaborators, Larry Hart and Oscar Hammerstein, were first-rate lyric writers. Richard Rodgers composed the music for the songs. Because he had been so successful in working with the two different lyricists, he was often asked how it was to work with the two men and how they differed. It needs to be mentioned that Hart was a very short man, about five foot three inches; Rodgers himself was only a few inches taller, and Hammerstein was over six feet tall. Rodgers said, "When I was working with Larry Hart, people would see us together and they would say, 'The little fellow is okay, but watch out for the big one. He is a snake.' Now when I was out walking with Oscar and someone recognized us, people would say, 'The big guy is okay, but watch out for the little one. He is a snake.' And that is the difference between working with Larry and working with Oscar."

Collaboration between the National Institute on Disability and Rehabilitation Research (NIDRR) and the President's Committee on Mental Retardation (PCMR) is like the collaboration described in this anecdote about Richard Rodgers and his distinguished collaborators, Hart and Hammerstein. (Now, I am not about to say which of us is more like Richard Rodgers - a.k.a the snake.) In good interagency collaboration, like the one between NIDRR and PCMR, both agencies retain their own basic characteristics, and their missions and their differences contribute to the success of the enterprise. Both make their unique contributions to the solution of problems, to the development of new strategies, and the generation of ideas that would never have been identified had the two agencies not collaborated.

In the interagency collaborations between NIDRR and the President's Committee, the differences are like those between the lyricist and the music composer. One of us supplies the music and the other supplies the words that give the singer (the

service provider, the scientist, the parent, the family member, and the individual with mental retardation) a song to sing, a job to do, and a dream to achieve.

Good interagency collaboration is based on the recognition that working alone results in less successful products. Richard Rodgers wrote few musical comedies by himself. Only one of these, No Strings, approached the kind of success he experienced when he collaborated with Lorenzo Hart or Oscar Hammerstein II. Richard Rodgers may well have been the snake in those relationships, but projects like Carousel and South Pacific would never have been achieved without the two collaborators.

What about the collaboration of NIDRR and PCMR? How do the two agencies collaborate? One way the two agencies collaborate is by supporting the work of one another. NIDRR, for example, is a co-sponsor of this summit and of past conferences of PCMR. PCMR assists NIDRR in the identification of research priorities that have the potential to benefit individuals with mental retardation. It participates as a member of the Interagency Committee on Disability Research that I chair as Director of NIDRR. For you to understand the ways in which NIDRR might collaborate with PCMR and individuals having mental retardation and their families, I think it is important that you know more about NIDRR.

NIDRR is located within the Office of Special Education and Rehabilitative Services of the Department of Education. It is a federal agency that has the mandate to provide a comprehensive and coordinated approach to the administration and conduct of research, demonstration projects, and related activities for the rehabilitation of individuals with disabilities, including programs designed to train persons who provide rehabilitation services and persons who conduct research. NIDRR is also charged with the responsibility of facilitating the distribution of information concerning developments in rehabilitation procedures, methods, and devices to rehabilitation professionals and to individuals with disabilities to assist them to live more independently in the community. NIDRR is further charged with the distribution of technological devices and equipment for individuals with disabilities by providing financial support for the development and distribution of these devices.

In federal fiscal year 1991, the NIDRR has an annual budget of $84.9 million. This amount includes the basic NIDRR appropriation of $58.9 million, model spinal cord injury projects ($5.0 million), and the Technology-Related Assistance Act, Titles I and II ($20.10 million).

Of $84.9 million, $3.59 million has been programmed for disability and rehabilitation research in the area of mental retardation. What kinds of projects are

funded? A Rehabilitation Research Training Center (RRTC) is funded at the University of Minnesota to improve community integration for persons with mental retardation. There is a second RRTC funded at Syracuse University to identify and focus its efforts on actual practices for operating community residences for children and adults with mental retardation. There is an RRTC at the Cincinnati Center for Developmental Disorders to provide expertise in helping older people with mental retardation integrate into community life. There is an RRTC at Virginia Commonwealth University designed to improve employment outcomes for individuals with mental retardation by using the supported employment model. These four activities are examples of the kinds of work being carried on by NIDRR grantees that promote the integration and inclusion of individuals with mental retardation into the community. Funding also occurs in the Field-Initiated Research, Innovation Grant, and Small Business Innovative Research Program.

Thank you for inviting me to speak with you about the important issue of interagency collaboration. I know that NIDRR and the PCMR will continue to work together to promote collaboration and excellence in research and services for people with mental retardation and their families.

Summit Panel IV

IMPROVING THE HEALTH STATUS OF CHILDREN

February 7, 1991

MODERATOR: Rudolph Hormuth

Specialist in Services to Mentally Retarded Children
Maternal and Child Health Bureau
Public Health Service
U.S. Department of Health and Human Services
Bethesda, Maryland

PANELISTS: Michael E. Vader
Judy Schrag, Ph.D.
Judy Howard, M.D.
Herbert J. Cohen, M.D.
Travis Thompson, Ph.D.

PROVISIONS OF THE EDUCATION OF THE HANDICAPPED ACT -- PART H

by Michael E. Vader
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Washington, D.C.

Good Morning! It is a pleasure to be here at this conference of the PCMR. I bring greetings from Dr. Davila and the rest of the staff at the Office of Special Education and Rehabilitation Services (OSERS). Dr. Davila regrets that he cannot be here with you for this conference and sends best wishes for a fruitful and productive meeting.

When I was asked to deliver remarks, I accepted gladly, since this will give me a chance to talk with you about some of the exciting things which are going on in our office. After my remarks, Dr. Judy Schrag will be speaking to all of you and providing you with additional information on special education-related activities which are directly relevant to your work.

Upon our arrival at the Department of Education, one of the first actions taken by Dr. Davila and me was to work with OSERS staff to develop a new mission statement for the agency. This mission statement emphasizes that the goal of all the educational and rehabilitative services we provide for persons with disabilities is to help them achieve maximum participation and productivity in society. This is the cornerstone of all of our efforts at OSERS.

In the past several decades, our view of what it means to have a disability has changed greatly. For most of history, the focus of thinking about the lives of persons with disabilities has been on their limitations. The dominant way of responding to the needs of persons with disabilities was in terms of charity or pity. This approach encouraged the development of programs and institutions which made possible better lives for these individuals, but this way of thinking also had its drawbacks. Charity usually went hand-in-hand with a tendency to underestimate the ability of persons with disabilities to shape their own lives. But as time went on, these attitudes slowly changed. More and more persons with disabilities, parents and professionals began to question the assumptions of the past. A new view of disability began to emerge. There was an

increased emphasis on the ability of people with disabilities to determine their own destinies.

These changes in attitude had tangible effects. One result was the movement to deinstitutionalize individuals with developmental disabilities. Another was the movement among people with disabilities to develop self-help programs that supported them in their efforts to live independently in the community.

Along with these innovations came the understanding that, all too often, society imposes needless obstacles to full social participation by persons with disabilities. All of these developments share a common theme. They each contribute to the increased social integration of persons with disabilities. As our philosophy continues to grow toward an attitude that promotes full integration in our society, our programs and services will also grow with it. Many of the programs that we now take for granted as essential parts of a sound education and rehabilitation experience began as ideas which were contrary to present practices and beliefs.

One of the best examples of such a systemic change is embodied in the education of the Handicapped Act (EHA) amendments of 1986, Public Law 99-457. This landmark legislation amended the initial EHA, which was originally passed in 1975. I am sure that all of you are aware that EHA was reauthorized in October 1990, and it is now called the "Individuals with Disabilities Education Act" (IDEA).

However, it also added two new programs: the Early Intervention Program for Infants and Toddlers, and a greatly expanded version of the Preschool Grant Program. The Preschool Grant Program was, to this point, a small incentive grant program which provided small amounts of money to states for each preschool-age child who received all of the services, rights, and protections afforded to school-age children.

Until the adoption of these two programs, the Congress focused primarily upon the needs of school-age children with disabilities, believing that Federal dollars would be best spent in concentrating on the older population of students with disabilities, and thus went the general thinking of the day. In recent years, however, more and more research began to demonstrate that providing preschool and early intervention services to young children often yielded important and lasting benefits to both the children and their families. The changed perception of disability which was signified by this research had important implications for special education and other disability programs.

In 1983, the Congress established a state planning grant program under the Early Education Program for Children with Disabilities that provided small grants to states for

planning and implementing services to children with disabilities from birth through 5 years of age.

But by the 1985-86 school year, only 24 states had mandated special education and related services for all children with disabilities, beginning at 3 years of age or younger, and only six states mandated services beginning at birth. Thus, while some progress had been made through Federal incentives, discretionary projects, and state planning grants, the majority of states did not provide early intervention and preschool programs for all young children with disabilities. Federal intervention was needed, and by that time, advocates were exerting substantial pressure on the Congress to enact comprehensive early intervention legislation for birth through 2-year-old and 3 through 5-year-old children with disabilities. In response, the Congress held a number of hearings, and enacted P.L. 99-457 on October 8, 1986.

The Part H Program for infants and toddlers is a formula grant program of assistance to states to help them develop a comprehensive, interagency program of early intervention for infants, toddlers, and their families. Not only are children birth through two years of age eligible for services under Part H, but in addition, states may elect to serve infants and toddlers who are at risk for delay if early intervention services are not provided.

One of the most significant features of the Part H Program is its emphasis on the family. Both children and families must be assessed to determine their strengths and needs, and early intervention services must be documented in an individualized family service plan. Early intervention services may include case management services, family training services, health and medical services, and others.

We're very excited about the future of programs that provide early intervention services for infants and toddlers. We're now into the fourth year of implementation. All states have applied for third-year Part H funds, and 16 for year-four money. We have awarded fourth-year funding to about 10 states thus far.

In addition, the Part H program went from a funding level of $79 million for fiscal year 1990 to $117 million for FY 1991--an increase of $38 million. We are hoping that this a trend that will continue.

P.L. 99-457 changed the small preschool program from an incentive grant program to a program that, beginning in 1991, requires the provision of services to all preschool children with disabilities, 3 through 5 years of age. The program awards

formula grants to states and territories on the basis of their share of the total number of children in the 3-through-5-year age range who are being served.

The new preschool program effectively extends all of the services, rights, and protections afforded to school-age children under P.L. 94-142 to preschool-age children with disabilities. If a state does not serve all 3 through 5 year olds with disabilities by 1991, it cannot receive funds under this program or under the grants to states and Chapter 1 programs. The state would also be subject to other financial sanctions.

In our work at OSERS, we have established a mission to ensure that all individuals with disabilities realize their optimal potential, productivity, and participation in our society. Young children have so much potential. They are at the beginning of their lives. By making sure that young children with disabilities and their families receive the support and intervention that is needed, we have the best chance of helping them to reach their full potential. Even from the time of early childhood, our goals must be focused on outcomes and the long-term productivity of children and families. We can do this only if there is a long-standing commitment between parents and professionals to work together in partnership to provide the necessary services.

The individual family services plan gives us a method for thinking about what outcomes we want for children in the short term, and in the future. The IFSP enables us to plan for the transition between infancy and preschool, when the bridge will be made between the IFSP and the IEP.

Right from the start, parents and interdisciplinary professionals need to be partners so that full participation in the planning process is realized. This will help ensure that our young children are fully-fledged, participating members of society, that families are not isolated, and that services will be made available where children need them within community settings. I believe that this is of prime importance.

Service delivery must be a normal part of a child's life, rather than a disruption in that life. Service delivery must become part of the normalizing process, rather than something that hampers normalization. Involvement by concerned and vigilant parents will continue to ensure that emphasis will be placed on quality services at the local level.

This need for full participation in the planning process is also true at the Federal level. Our efforts to expand programming for infants means that we will be dealing with many new issues. I think it is vitally important to the future of people with disabilities that we cultivate hope and confidence. It is only when we possess these attitudes that we

can embrace and master change. If we respond positively, we will continue to develop the innovations required to ensure equal opportunity for persons with disabilities.

At the Office of Special Education and Rehabilitative Services, we are committed to supporting these efforts. We view ourselves as your partners in developing more responsive programs. Together, we can build a system that will make it possible for all persons with disabilities to reach their full potential.

Thank you for inviting me to be here with you today, and best wishes for success in your deliberations.

OFFICE OF SPECIAL EDUCATION PROGRAMS:
COORDINATED SERVICE DELIVERY FOR A
CHANGING POPULATION OF STUDENTS WITH DISABILITIES

by Judy Schrag, Ph.D.
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I am very pleased to join my colleagues here at the table to be a part of this important Summit on the National Effort to Prevent Mental Retardation and Related Disabilities. As you no doubt know, a year ago the nation's governors joined President Bush to establish some national education goals. The first goal, very appropriate to this conference, is a readiness goal to provide services and programs for children so that they are ready to come to school to learn.

This goal is particularly critical to children with special needs. Mike Vader has talked about the infant and toddler program, that is the birth through two years. I am going to move up on the age range, still emphasizing readiness, the changing population of moving down to birth, and talk about the 3- to 5-year-old range. As I begin, I am going to put one overlay on the screen. As of January, 1991, all states continue to indicate that they are participating in the Part H Infant and Toddler Program to which that Mike Vader referred. If you look at our progress toward providing services, down to birth, for children with disabilities, this chart shows that all states and territories, with the exception of seven, have preschool mandates for children beginning with age three.

Two states, Indiana and North Carolina, have passed a mandate, but their mandate is contingent upon funds appropriated by their legislature; that is, a year-by-year determination. In order to continue to receive pre-school Federal funds, that is, formula funds as well as discretionary funds, they must have their preschool mandate in place by this fall. Continued eligibility for Chapter 1 handicapped funds and other discretionary funds for preschool are also contingent upon passage of a state preschool mandate.

Congress is very serious about movement of services, down to birth, and the Part H program; as a matter of fact, right after the break I will go back and we will start our briefings for Congressional staff today regarding the re-authorization of that program. The Infant and Toddler Part H program is currently up for re-authorization. There are a number of issues that Congress will consider within the re-authorization process.

For example, changes will be considered to insure that children being served in the infant and toddler program transition well to the 3-5 preschool program and then to the school programs for school-age students.

Both the Part H and the state and Federally-funded preschool programs can help children attain the readiness skills to begin school ready to learn.

In my few minutes this morning, I want to talk about two or three things. First, I want to highlight the priorities that the Office of Special Education Programs has just published in the Federal Register for the use of discretionary early childhood programs that support preschool mandates within the states. Congress has passed two pieces. One is the formula program which is $292.8 million this year or roughly $1,000 per child. In addition, Congress has appropriated another $24.2 million during this current fiscal year for discretionary programs; that is, training, research, and demonstration to support program efforts within the states.

We have published in the January 22 Federal Register our priorities for the fiscal year 1991. The first priority is to continue to support demonstration projects. These demonstration projects are non-directed and are intended to support services for children that are in an integrated and normalized setting. The second priority is to support outreach projects. Outreach projects help build the capacity of educational and other agencies through the implementation of proven practices or those that other states have proven effective across the country, either the model itself or selected components.

The third early childhood priority for fiscal year 1991 is non-directed experimental projects which are investigations of affective models. We are particularly focusing on families, parents of young children, particularly whose families who are members of minority groups or who are bilingual. Our fourth early childhood discretionary program priority supports capacity-building projects. These projects develop, demonstrate, evaluate, and disseminate in-service training models because of the extensive personnel needed to implement Part H, birth through 3, and the preschool programs through age 6.

The fourth early childhood priority will be to establish an early childhood research institute which will identify service patterns and gaps for children at-risk and to look at eligibility criteria, identification instruments, funding sources and so forth. I am excited about the fourth priority because it deals with a very definite changing population -- the population of children prenatally exposed to crack cocaine. This priority will support an early childhood research institute to develop, field test, and disseminate new collaborative approaches for this population of children.

The population of children that we are serving in special education and related services is very definitely moving, down to birth. There is great excitement across the country in this area.

There are other changing populations on which we are focusing our efforts in the Office of Special Education to support efforts within your states. For example, we know that the schools are faced with increased numbers of severely handicapped, medically-fragile children who might have died a few years ago but are being saved and entering our classrooms as a result of wonderful medical technology. Another aspect of the changing special education population is that new medications are being used for cancer, epilepsy, and emotional problems; some that are appearing to permanently affect learning skills. Increased numbers of scoliosis students are now returning to school without extended home and extended hospital stays.

Other aspects of the changing population include children with cystic fibrosis, muscular dystrophy, and hearing defects who are living longer than in previous years and are, therefore, entering our schools. In addition, there are increased numbers of HIV-infected babies as well as greater ethnic diversity. Congress has recognized younger and more impacted students with emotional disturbance and mental health needs with a new discretionary program in the IDEA or the re-authorization of the Education of the Handicapped Act. We have other changes in our special education population. Certainly, this increased diversity demands a whole-child, coordinated service delivery approach. There are many exciting new linkages being formed across special education, social services, and health services within the states. Today only allows highlighting some of those. The CASP projects and Robert Wood Johnson-supported projects for children and families with mental health concerns are some examples.

Tomorrow the Federal Interagency Coordinating Council (FICC) is meeting. While the focus of the FICC is Part H, we will be expanding and looking at linkages for school-age and other changing populations as well, trying to look at the interfaces between our various programs, the boundaries, cross-cutting issues, barriers in policy; funding barriers, and the incompatibility of laws, rules and regulations. There are many examples of interagency collaboration at the Federal level.

Just to mention a couple, we are jointly funding projects with Maternal and Child Health. For example, we have a jointly-funded project at the University of Utah which I think is a very important one, dealing with prevention of hearing impairments. This project is looking at a computerized screening for children relating to the Surgeon General's recent goal; that is, by the Year 2000, 90 percent of children born with hearing

impairments will be identified by 12 years of age. This project is investigating new screening technology and capability for application across the states.

There are lots of examples of projects and efforts across agencies. I have spent my time focusing on the three to five-year-age range, as well as other changes in our population. We simply are not serving the same children in special education and related service areas as we have been in the last few years. A very important focus at all levels -- local, state and Federal -- is to look at new delivery systems that focus on collaboration across mental health and social service personnel in the schools, lots of continued option changes that make our continuum more fluid and more dynamic, and I will close at this point.

Thank you.

THE IMPACT OF SUBSTANCE ABUSE AND TERATOGENIC FACTORS ON CHILD DEVELOPMENT AND FAMILY OPTIONS

by Judy Howard, M.D.
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During the past two decades, patterns of chemical dependency have shifted from a primarily male population of heroin abusers to a population where polysubstance abuse is the norm and a significant percentage of abusers are women, many of whom are of childbearing age. Consequently, treatment efforts also have shifted from an emphasis on methadone maintenance programs to programs that include a family focus. These changing patterns have resulted in a new group of families with special needs that must be addressed by professionals from a range of disciplines, including medicine, nursing, social work, mental health, special education, psychology, drug and alcohol treatment, and law. In addition, specialized training regarding chemical dependency and its impact on family functioning is critical.

Chemically dependent families have some characteristics that are similar to those families whom many of us are accustomed to serving, i.e., those with developmentally disabled children, particularly with respect to two common denominators: (1) the children are biologically at risk for developmental problems, and (2) the rearing environments must be uniquely structured in order to support the children's optimal health and development.

Biological risk implies a possible or confirmed health problem or developmental impairment in the domains of behavior--gross motor, fine motor, cognition, language, and personal-social skills. The classic examples of biologically impaired and at-risk children include those with pediatric AIDS, congenital heart disease, pulmonary disease, cerebral palsy, birth defects, mental retardation due to known genetic causes (i.e., chromosomal abnormalities), birth asphyxia, in-utero viral infections (i.e., rubella, herpes, etc.), and preterm birth.

Children who have been prenatally exposed to drugs and/or alcohol also fit into this category of biological risk. About one third of drug-affected children are born preterm, which makes them biologically vulnerable on two fronts. First, they may have complications related to their prematurity that can include intracranial bleeds, visual

handicap, cerebral palsy, and/or learning problems; and second, they may have biological complications stemming from the effects of their mothers' prenatal drug use on the developing organ systems of the fetus. The remaining two thirds of this group, who are born fullterm, are also at risk for developmental problems resulting from the effects of prenatal drug exposure.

The topic of this presentation, the impact of substance abuse and teratogenic factors on child development and family options, is not a new concern. In 1976, the National Institute on Drug Abuse published the results of a symposium on comprehensive health care for addicted families and their children. Some of the major researchers working with chemically dependent women and their children presented at that symposium. Their closing remarks reflected the following considerations: Infant mortality and parental problems are high in this population, there is an increased incidence of obstetrical and medical complications in women who abuse substances during pregnancy, as well as a high rate of low-birth-weight infants. Further, one developmental pediatrician commented, "I have observed the growth and development of narcotic addicts' infants for the past ten years. . . . We are concerned that narcotic-affected infants, even when raised in stable environments, have behavioral, neurologic, and growth characteristics different from those of other high-risk babies."

Newborn Status of Drug/Alcohol-Affected Infants

There are numerous publications addressing the entire spectrum of substances used by women during pregnancy--including alcohol, nicotine, marijuana, heroin, methadone, cocaine, and phencyclidine (pcp)--that can interfere with fetal growth. Findings consistently confirm that newborns exposed to these various substances are shorter, have lower birth weights, and/or have smaller head circumferences than non-drug-exposed infants.

A single causative agent of impaired physical growth is unlikely. Fetal growth is affected by the complex interactions of the dietary intake of the mother, the energy requirements of the mother and fetus, maternal cardiovascular function, and the performance of placental functions (including metabolism and transfer), as well as fetal physiology and use of nutrients. In addition, separate from nutrition and oxygen requirements, growth factors and hormones also affect fetal growth through their action as regulatory elements. As one noted nutritionist has commented, "The growth of the fetus is a very sensitive process."

A variety of physiological changes brought about by cocaine, amphetamines, heroin, and PCP in the adult user have been described. Cocaine, amphetamines, and

PCP, for instance, are known to cause increased blood pressure in the adult user, and if that individual is pregnant, research has shown that these substances are transferred through the placenta into the fetus, causing further physiological changes in fetal blood pressure, heart rate, and metabolism. The energy requirements of a heroin user going through withdrawal are also well recognized. Increased caloric consumption occurs, as well as changes in blood pressure, and these, in turn, can affect fetal growth in a pregnant user. These are only a few examples of the pharmacological actions of some common substances of abuse.

Specific research regarding the potential teratogenicity of cocaine upon the developing fetus has noted an increased incidence of spontaneous abortion, placental abruption, prematurity, intrauterine growth retardation, and neurological deficits in the infants of women who abuse cocaine. Furthermore, it has been suggested in recent studies that fetal vascular disruption accompanying maternal cocaine abuse may lead to cavitary central nervous system lesions, genitourinary anomalies, congenital limb reduction defects, and/or intestinal atresia or infarction.

When studying the developmental course of children exposed prenatally to drugs, in addition to the pharmacokinetic characteristics of common substances of abuse, one also must recognize the confounding effects of the lack of adequate health care, presence of sexually transmitted diseases, and exposure to AIDS and/or hepatitis that frequently occur in this population, as well as the nutritional status of a chronic addict. All of these factors are known to interfere with adequate fetal growth.

Although not all children who have been prenatally exposed to drugs and/or alcohol experience abnormal perinatal events and problems with long-term development, there is strong evidence for the existence of a continuum of reproductive casualty ranging from spontaneous abortion and fetal death to prematurity, intrauterine growth retardation, mental retardation, learning problems, and normalcy. In 1985, one researcher noted that some children of mothers on methadone demonstrated no long-term effects, while the outcome for others was guarded due to abnormal developmental scores up to 84 months of age and a higher incidence of referrals for behavioral and academic problems. My colleagues and I have reported similar findings within a group of children exposed prenatally to PCP and cocaine who had different outcomes by 15 months of age, in spite of comparable histories of maternal years of drug use, frequency of use, lack of prenatal care, and use of nicotine, alcohol, and marijuana. Some toddlers had normal head circumferences and developmental scores, while an even larger group demonstrated head circumferences below the tenth percentile and significantly lower developmental scores. Resiliency occurs, but at this time we do not have the expertise to determine why some children are spared and others are not.

Behavioral Developmental Patterns

When addressing the issue of long-term development in high-risk children, one must consider the interplay between the biological and environmental factors that influence observed behaviors. Researchers who have examined long-term developmental patterns of behavior have taken particular care to recognize that continued exposure to the instability, disorganization, and emotional upheaval associated with the drug culture places a child at even greater risk for long-term developmental difficulties. In view of this environmental risk status, investigators have carefully described specific behaviors in drug-affected children that may be attributed both to biological and environmental causes.

In a 1976 study, toddlers who were exposed prenatally to heroin and methadone had overall scores within the normal range, although behaviorally they were found to be highly energetic, active, talkative, and quite reactive to sensory stimulation. Additionally, although they appeared to be very interested in toys and objects as well as in people, their overall persistence, goal-directedness, and attention spans appeared to be rather brief. During play, these children seemed immature and often mouthed and banged the toys rather than demonstrating more complex manipulations and constructive play. In a further study in 1985, examining the long-term effects of prenatal methadone and polysubstance exposure, 24-month old children seemed to have particular difficulty with tasks that were highly structured or involved verbal instructions.

With these findings in mind, several years ago my colleagues and I made an effort to quantify the organization of unstructured play behavior in toddlers whose mothers were polysubstance abusers. In spite of normal developmental scores, these youngsters, who had not experienced perinatal complications, showed significantly altered ability to structure play sequences requiring focused attention, sequencing of activities, and persistence with any single scheme of play (i.e., feeding a baby doll and putting the baby to bed), as compared with a group of preterm infants who had been respiratory dependent following birth but who had normal developmental scores. With regard to environmental influences, we found that those prenatally drug-exposed children who had secure relationships with their caregivers demonstrated better organization in play and better attention spans than those who had insecure attachments.

Clinical reports of behaviors in older children also have been published. In 1979, in a group of preschoolers who were prenatally exposed to heroin, one team of researchers found that the parents rated these children as having greater difficulty with self-adjustment, social adjustment, and physical adjustment. Areas of significant difference included uncontrollable temper, impulsiveness, poor self-confidence,

aggressiveness, and difficulty in making and keeping friends. Still, the children's overall performance was within the normal range with regard to intellectual functioning.

The late childhood and adolescent behaviors of children exposed prenatally to drugs have not yet been documented. However, one large ongoing longitudinal study examining the behaviors of adolescents exposed prenatally to alcohol and living in middle-class homes may provide a possible scenario. The research team reports that many of these children present with learning problems in school, short attention spans, impulsivity, and poor socialization. In fact, the principal investigator of this study has expressed to me her concern that existing vocational rehabilitation programs will not be able to effectively assist these young adults, since their needs are different from those of individuals with developmental disabilities that include physical handicaps and mental retardation.

Conclusion

Many systems are already in place to serve disadvantaged and/or biologically at-risk infants and children. For instance, children living under impoverished circumstances can receive health care funded through Medicare, and supplemental food can be provided through WIC programs. Infants and young children who are at risk or have developmental disabilities are eligible to receive services through developmental disabilities programs such as Regional Centers in California. Through Public Laws 94-142 and 99-457, special education programs are and will be available to serve this special-needs population of children from birth, as well as their families. These programs also will provide services for infants who have been exposed prenatally to drugs. However, in order to appropriately serve this particular group of children and their families, some existing programs must be modified, and additional services must be considered.

Substance-abusing families bring unique challenges to our current service delivery system, where the primary caretaker (usually the parent) is responsible for bringing the child to health care and educational services. In order for a parent to ensure that the child is in the best of health and has educational opportunities, that parent must be able to locate and secure appropriate services. Based upon our knowledge about chemically dependent parents (i.e., altered mental status, the nature of addiction, the illegal activities revolving around drug use, etc.), health care providers, educators, and other involved professionals must be informed about the disorder of chemical dependency and its impact upon the daily life of the substance abuser. We cannot assume that chemically dependent parents will be able to advocate effectively for their children, work as team

members in providing for their children's health and educational needs, and follow through with professional recommendations on a consistent basis.

If we want these "special-needs parents" to participate in the models we have developed, we will need to ensure that the parents themselves receive treatment for their addiction as well as parenting education and mental heath services. Furthermore, in cases where children have been temporarily removed from their biologic parents' custody by court order and are under the care of extended family members or foster parents, or are in congregate care homes, we also will need to provide information to these temporary caregivers to help them obtain appropriate health and educational services for the children. We will need to identify the needs specific to these various caregivers (including grandparents, aunts, and foster families) and provide supportive services to them, as well, to insure that they are able to participate fully in the children's individualized health and education plans.

Providing these services will require the cooperation of professionals who traditionally have not been involved in meeting the health and educational needs of developmentally disabled children. Drug and alcohol treatment counselors, child protective services workers, law enforcement professionals, and members of the judicial system will need to join forces with medical and educational professionals so that chemically dependent families will receive coordinated treatment services for promoting a family unit that is healthy both physically and emotionally.

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PROFESSIONAL PREPARATION AND TRAINING TO MEET THE NEEDS OF MOTHERS AND CHILDREN WITH HIV INFECTION AND AIDS

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Introduction

Infection with HIV has rapidly become the leading infectious cause of mental retardation and developmental disability in the United States. By October 31, 1990, the Centers for Disease Control (CDC) knew of 2,686 reported cases in children under 13 years of age, with an estimated eight to ten times that number infected. Reportedly, between 1,500 and 2,000 children with an HIV infection were born in 1990 (CDC, 1990a). Forty-two percent of cases in such children will be diagnosed by one year of age. Worldwide, the World Health Organization indicates that there will be 10 million or more infants infected by the year 2000 (WHO, 1991).

To understand the consequences of Human Immunodeficiency Virus (HIV) infection in children, one must understand its epidemiology and the effects of HIV on the developing central nervous system.

Epidemiology

Pediatric Acquired Immune Deficiency Syndrome (AIDS) is due to an infection with the Human Immunodeficiency Virus. In children, most current cases are due to maternal in-utero transmission, primarily in the first trimester. Rare cases of infection due to breast feeding have been reported in the United States. In the earlier years of the HIV epidemic, there were more cases due to transfusion by blood or blood-derived products, especially among those children with hemophilia. Fortunately, through the use of techniques to screen blood for HIV, transfusion-related cases are now rare (CDC, 1990a and 1990b).

Transmission of HIV to the adolescent population and to adults with developmental disabilities is similar to that of the general population, either through sexual intercourse and/or IV drug use.

Neurodevelopmental Consequences of HIV Infection

In 1983, staff at our Center were asked to evaluate the developmental status of six of the earliest diagnosed cases of pediatric AIDS in the United States. All 6 were mentally retarded (Ultmann et al, 1985). Subsequent follow-up studies of groups of children with HIV infections in urban areas, such as the Bronx, New York and Newark, New Jersey, noted a 78-90 percent prevalence rate of neurodevelopmental abnormalities in these children (Epstein et al, 1985; Ultmann et al, 1987; Belman et al, 1988). In addition, among those with motor dysfunction, close to 50 percent had cerebral palsy-like symptoms (Diamond and Cohen, 1988).

Yet, more recently, studies in Europe have reported a much lower prevalence of moderate-to-severe central nervous system abnormalities associated with HIV infection. In these reports, closer to 20 percent of the infected children had such neurological findings (Tardieu et al, 1989; Cogo et al, 1990).

However, other factors may lead to neurodevelopmental dysfunction in children with HIV infections. These may include: mother's substance abuse during pregnancy; poor general health, nutritional status and inadequate overall prenatal care during pregnancies; the problematic general health, infectious complications and nutritional status of the child; the presence of chronic illness and its attendant psychosocial difficulties; and a variety of possible adverse environmental factors. Some or many of these factors may combine to lead to the discrepancies in findings about neurodevelopmental function in reports comparing American to European children with HIV infection.

It has been clearly shown that HIV invades the central nervous system and produces an apparent encephalopathy. Though the direct presence of the virus has been demonstrated, as well as infected mononuclear phagocytic cells in the microglia, along with macrophages and multinucleated macrophage-like giant cells, recent studies indicates that toxic substances are released in the brain that may be the principal cause of the damage inflicted by HIV (Giulian et al, 1990). The end result can be a varied picture of neuropathological findings that can lead to mental deterioration, progressive motor dysfunction, brain atrophy, and progressive dementia in both children and adults.

Prognosis

The neurodevelopmental course of symptomatic children with an HIV infection may vary widely. A prospective study, conducted at Albert Einstein College of Medicine of 64 children with HIV infections from New York City minority group populations, found that neurologic deterioration occurred in 62 percent of the children followed over a four-year period. Most of these children manifested a relentless progressive course with loss of previously acquired developmental milestones, cognitive deficits and worsening of long tract signs. Some children had a more smoldering course with "plateau-like" periods where deterioration was not evident. During these periods, the children showed none of the anticipated age-related developmental gains (Belman et al, 1988). Neurological deterioration often accompanied clinical deterioration in other body systems as well, especially in the immune system. There was a high mortality rate of 80 to 100 percent associated with these relatively short-lived courses. Most of the children died within 6-8 months of the onset of deterioration (Levy and Bredesen, 1988).

Children infected with HIV not only may have neurodevelopmental disorders, but they may also have immunological, physical, sensory, social, behavioral, and educational impairments or difficulties. Therefore, care for these children may require extensive diagnostic and treatment services from many medical and allied health specialists, as well as from special educators and child care personnel.

The complex nature of the child's and family's problems necessitates the development of a comprehensive service plan for the child and family.

The determination of the needs of the child and family or caretakers may vary considerably from case-to-case, as well as with the time in the life of the child with an HIV infection that he/she is either first diagnosed as having an HIV infection or is brought to the attention of service providers.

Training Requirements

Training needs include not only a familiarity with the previously presented information to convey an understanding of the causes, epidemiology, and course of the disease and its neurodevelopmental consequences, but also knowledge about the mechanisms for transmission of HIV, the forms of treatment, how to deal with the families and other caretakers, rights and entitlement of those infected, protection of confidentiality and who has the right to know, antidiscrimination measures and legal protection mechanisms, the complex moral and ethical issues associated with information

sharing, rights to privacy, and the rights of care providers to know who is infected, what are the new treatment approaches and the current data on prognosis.

Therefore, those who provide services for the child with an HIV infection and their family or caretakers must have an understanding of the disease, its cause, its social consequences, the devastation that it may cause and its varied impact at different stages in the course of the disease.

Many of these issues are already covered in Technical Reports, Public Policy Affirmations and Guidelines published by the Administration on Developmental Disabilities' funded Consortium Project, conducted by the American Association of University Affiliated Programs, the Boston Children's Hospital, Albert Einstein College of Medicine, the Morristown Center for Human Development and the National Association of Protection and Advocacy Programs (Cohen and Crocker; 1989, 1990). In addition, a specific publication on training-related issues and the mechanisms to convey such information is now in press.

To this body of information, I would like to add some up-to-date information about one of the most critical issues that administrators, staff, and trainers deal with when they discuss the problem of HIV infection, the concern about infectivity and contagion.

Limited Infectivity

Numerous studies have demonstrated that HIV is transmitted almost entirely through sexual contact or parenterally, with rare cases due to blood contact with mucous membranes also reported. Among health care personnel there have been a small number of cases resulting from accidental needle sticks.

Of importance to child care workers and those in the developmental disability field is that transmission among household contact and between children is almost nonexistent. Among the initial 100,000 cases of HIV infection reported to the CDC, no routine household contacts were reported to cause additional cases of HIV infection. Eleven studies of household contacts have yielded no evidence of intra-household transmission. Most recently, Rodgers et al (1990) studied 25 primarily preschool children with HIV infections. There were 89 close HIV negative household contacts who were followed from five to fifteen months. All remained negative during that follow-up period. The daily contacts with the child who was HIV infected included activities such as sleeping, bathing, hugging, biting, giving injections, extensive skin contact, and changing

diapers and linens. There was also sharing of utensils, toothbrushes, nail clippers, toilets, baths, combs, towels, toys and beds.

Only one well-documented case of spread from child to mother has been reported in a child with a congenital intestinal abnormality and one questionable case of transmission from a bite (while 30 other closely studied cases showed no transmission under these circumstances). Rodgers' study included nine cases of bites without transmission of HIV.

Therefore, the CDC and the American Academy of Pediatrics have indicated that there should be no barriers to children with HIV infection attending school or day care. Only precautions against blood contact using barrier protection are necessary, though routine hand washing is advisable with contact with all body fluids from all children is these settings (AAP, 1987, CDC, 1988).

Prevention

Since this is a conference on prevention, it is obviously important to emphasize that prevention of HIV infection should play a critical role in all consideration relating to HIV and is a key part of any training curriculum. AIDS education should begin early and be an important component of a curriculum that attempts to prevent sexually transmitted diseases and substance abuse. Training of staff in health, education, developmental and social services, and the public at large, must continually emphasize prevention measures.

Conclusion

Understanding HIV and its consequences is and will continue to be an important issue in the 1990s, but hopefully not beyond. There are some critical issues relating to HIV infection that everyone in the human services field and all trainees must understand. These include:

1. No discrimination is acceptable against anyone with an HIV infection .

2. Those with an HIV infection should have access to all the services, including developmental, that are available to anyone else.

3. The understanding of the disease is changing, as is the treatment which is becoming more successful in prolonging life, improving the quality of life, and in the case of children, apparently at least temporarily arresting the neurodevelopmental consequences of the disease.

As we learn more about HIV, we learn more about ourselves. For those that are in doubt about their capacity to personally care for persons who are HIV infected, it may be useful to remember the wisdom from a fortune cookie that stated "doubt is the beginning, not the end of wisdom."

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RETURN US THE CHILDREN--
SOCIETAL PREREQUISITES

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Poverty: Failure of Corrective Feedback:

The house in which I grew up was built around the turn of the century. The building had been refurbished after the second World War, complete with a thermostat which controlled the original cast iron coal furnace. As a child, I dismantled the thermostat and found it contained two laminated metal strips wound into a coil. As room temperature dropped, the metal strips contracted at different rates making the coil unwind and when the room temperature rose, the coil wound tighter like the spring of a windup clock. Mechanical contacts opened and closed to turn the furnace on and off. The old coal furnace maintained our house at a stable 68°F, plus or minus a degree or two, even when the outdoor temperature was -30°F.

As an undergraduate student, I learned in a zoology course that physical, biological, and social systems often employ such feedback devices. The mechanism controlling a person's heart rate involves a similar feedback system, as does the process regulating how much food we eat. How well a furnace regulates room temperature depends on sensitivity of a bimetallic coil and the ability of the furnace output to keep up with information provided by the thermostat. If the thermostat is sensitive to small temperature changes, room temperature fluctuates little. But if the coil requires a large temperature change before it coils or uncoils, or responds slowly to changes in room temperature, the resulting ambient temperature fluctuates widely.

Some feedback systems oscillate out of control when the response of the system can't keep up with rapid input changes, which is what happens when an automobile begins to "fish-tale" on slippery pavement. The driver attempts to compensate for the skidding rear end of the automobile, reacting too late, then overcorrecting. After several attempts, the automobile's swings climax in an uncontrollable spin.

Feedback systems aren't always obvious when there is a lag between the cause and the feedback effect. We eat a few hundred calories too much today, tomorrow and

the next day, but don't notice the thicker waistline until weeks later. The body's psychological version of the thermostat is not sufficiently sensitive to detect small changes in body weight, and to change our eating habits. A single mother living in poverty can't afford nutritious food for her infant, then discovers five years later when he enters kindergarten that the child has difficulty learning to read, due to his early malnutrition. Those of us who are more affluent insist on paying less taxes today, which provides the single mother living in poverty without enough money for food for her child. Years later, we find ourselves paying more taxes for that child's special education, health care, and social service costs. Failed feedback systems are ubiquitous, while the link between our actions today and the delayed consequences elude us.

Unlike the furnace, which if turned off can usually be restarted, biological and social systems often sustain permanent or long-lasting damage from failure of feedback to regulate output. The pregnant mother's use of cocaine is controlled by feedback from the cocaine reaching her brain, but the undetected, damaging effects on her developing fetus has no influence the mother's cocaine use. Those damaging effects aren't detected for many months, and in some cases, the mother may not see them at all, since many women addicted to cocaine are incarcerated or abandon their newborn infants. As individual members of society, our actions that create the conditions favoring the mother's cocaine use are remote from the child's brain damage so that feedback has limited impact on our own behavior. We look for proximal causes of our own anxiety (e.g. criminal activity) rather than long-term feedback loops involving our own actions or inactions--those having lasting impact.

The consequences of poverty in America accumulated from 1960 to 1980, then sharply accelerated over the past decade. Like the thermostat that is insensitive to small changes in room temperature, we did not detect these incremental societal changes. Similar to the automobile accelerating into an uncontrollable spin, we suddenly realize we are in an emergency situation and frantically search for solutions. Gross disturbances surround us at every turn--homeless people sleeping on the street and eating out of garbage cans, pervasive drug-related crime, widespread neglect and abuse of infants and children, and disregard for the humanity of our older citizens. We have finally begun to realize that we all face major problems.

The Extent of the Problem

Two decades ago, Grace Hechinger wrote in the Wall Street Journal, "Poor children have disappeared, if not from the slums, then at least from the language. First they became 'deprived,' then 'disadvantaged', and finally 'culturally disadvantaged,' as though they lacked nothing more serious than a free pass to the Lincoln Center." An

Easter morning not many years ago, I drove past the Minneapolis Armory which was serving as a public food distribution center and saw a line of men, women, and children, blocks long, waiting for free food. A newspaper article about hunger in Minnesota reported, "the greatest increase in need for food appears to be in the outstate areas..." in which free food distribution had increased from 57 to 287 percent in some of the Northwestern farming areas. Minnesota is not unique. The same pattern is seen nationwide with 21 percent of children in the United States living below the poverty line, and black (46 percent) and Hispanic (39 percent) children suffering disproportionately the consequences of poverty. Haggerty and colleagues (1975) referred to this as "The New Morbidity," a term which has taken on a new meaning with burgeoning health and psychosocial problems such as drug abuse, child neglect and abuse, unemployment, mental health problems, illiteracy, delinquency, and increased risk of mental retardation (see Baumeister, Kupstas and Klindworth (this volume). Poor Americans suffer in death as well as life. A study by the Coalition for the Homeless in New York City found that 47 percent of the children who died under one year of age in that city were from indigent families, and were buried in mass graves on Potters Field on Hart Island in order for New York City to save money (Martin, 1990).

As a nation we have become accustomed to seeing mentally ill and chemically dependent people eating out of garbage cans; and watching television reports of babies being born whose brains had been bathed in cocaine for nine months prior to birth. In Crime and Punishment, Dostoyevski wrote, "Man grows used to everything, the scoundrel," and indeed, we seem to. We have learned to look the other way. Another generation of children born into poverty is being destroyed before our eyes, and far too little is being done to prevent that from happening.

Alarming changes have occurred in the way many view their responsibilities to fellow human beings. Some of our greatest challenges involve proper prenatal care for pregnant women and pre- and postnatal care for their infants. In a New York Times article, Anna Quindlen described "the ignominy of being pregnant in New York City." She wrote, "I love New York...It's a great place for half-sour pickles, chopped liver, millionaires, actors, dancers, Akita dogs, nice leather goods, fur coats, and baseball, but it's a difficult place to have any kind of disability, and as anyone who has filled out the forms for maternity leave lately will tell you, pregnancy is considered a disability." Ms. Quindlen continued, "New York has no pity: it's every man for himself, and since you're a yourself-and-a-half, you fall behind. There's a rumor afoot that if you're pregnant you get a seat on the A train. It's totally false!" Imagine the day-to-day lives of poor women who are pregnant and living in poverty. Lack of adequate food to eat and insufficient money to even afford the subway ride so they can see a doctor through the first two thirds of their pregnancy, makes concern about whether they manage to find a

seat seem trivial. But Ms. Quindlen's tale of shabby treatment at the hands of her fellow New Yorkers *is not trivial*; it provides a framework for beginning to appreciate how bad things are for women who are pregnant and poor.

Facing Up to the Problem

Being poor alone does not cause adverse developmental outcomes. However, the consequences of experiencing the conditions associated with growing up in poverty are not in doubt. Under-nutrition, inadequate prenatal health care, exposure to toxicants and infectious diseases in utero and in the surrounding external environment, unsafe living conditions, living with parents who are addicted to alcohol or other drugs of abuse, inadequate educational opportunities, are all more common in poverty circumstances. Children attempting to rear children (e.g., resulting from teenage pregnancy) produces predictable results. Not only are learning and behavior problems more common among children growing up in poverty, but mild and more severe forms of mental retardation are also more common (Butler, et.al. 1984; Broman, et.al., 1987; Institute of Medicine, 1985). AIDS is the most rapidly growing cause of death among teenagers in some inner cities, and the transmission of this disease to the fetuses by infected mothers is a growing cause of concern (Miller, Turner & Moses, 1990).

The recent report of the United States Inspector General indicates that approximately 100,000 babies are born in the United States each year who have been exposed to cocaine during pregnancy. The vast majority are born in public inner-city hospitals. The projected costs of caring for and providing services for these children are staggering. The Inspector General's report projects the cost of care for 8,974 crack exposed babies through the age of five in eight of the hardest hit cities, to be $500 million (Kusserow, 1990). If the 100,000 prevalence figure is accurate, that would represent a cost of approximately $1 billion per year in care for such children over the next few years. If the current trends persist, by the year 2000 over 10 times the number of cocaine-exposed children could require such costly care. Poverty has an unimaginable economic as well as human price tag.

The time has come when the young join the not-so-young in setting a new course for the future of our children. Those of us in the not-so-young category re-read Wallace Stevens' "The Man With the Blue Guitar" with a perspective the author could not have anticipated when he wrote these lines toward the end of the Great Depression.

The man bent over his guitar,
A shearsman of sorts, the day was green.

They said, "You have a blue guitar
You do not play things as they are."

The man replied, "Things as they are
Are changed upon the blue guitar."

And they said then, "But play, you must,
A tune beyond us, yet ourselves,

A tune upon the blue guitar
Of things exactly as they are."

This past century's experiences have changed us from the nation of naive optimists we once were. We have begun to see many more things around us as they really are. Facing the problem is half the battle, but the other half, engaging in a genuine search for solutions, requires a commitment of resources. Laurence Shames, author of The Big Time: The Harvard Business School's Most Successful Class and How it Shaped America, in a searching examination of business and academic values remarked, "Fewer people are drawn to the cutting edge of noncommercial scientific research...Fewer are asking the questions that matter...Fewer are putting themselves on the line, making as much of their minds and talents as they might...Does it ever occur to them that frequently success is what people settle for when they can't think of something noble enough to be worth failing at?"

Tackling problems associated with poverty is not a challenge for the faint of heart. The time is overdue that we stop shrinking from our responsibilities. Governmental agencies, businesses, and universities cannot solve these problems single-handedly, nor can any of these institutions be absolved of responsibility from joining the struggle. The 1990s will be the decade of combined efforts to solve societal problems that no single field of endeavor can reasonably expect to unravel alone. The results of yesterday's basic science will be today's applied research and become tomorrow's practice. It will be a time to turn difficult challenges into opportunities. It will be a time in which we will re-learn to take chances tackling problems that are truly important.

Authentic solutions are no longer rejected out of hand, but few political leaders are willing to take the chance of leading. Television and campaign financing have indelibly changed the meaning of leadership in America. One must look to leaders of an earlier time to find guidance. President John F. Kennedy's 1961 inaugural address called upon Americans to correct social inequalities, provide adequate health care and education for all Americans, and take dramatic new strides in technology. He said, "All

this will not be finished in the first one hundred days. Nor will it be finished in the first one thousand days, nor in the life of this Administration, nor even perhaps in our lifetime on this planet. But let us begin." It is time to begin...again. It is time to resume seriously working toward those noble goals, and to behave more responsibly as a people. It is time to capitalize on scientific knowledge so laboriously acquired over the past three decades and to strike out in search of new solutions where critical information is lacking. It is time to permit corrective feedback to work, to allow ourselves to be the kind of people we can and ought to be, for the sake of our children.

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Summit Panel V

EXEMPLARY STATE PLANNING TO PREVENT MENTAL RETARDATION AND RELATED DISABILITIES ASSOCIATED WITH SOCIOECONOMIC CONDITIONS

February 7, 1991

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FLORIDA'S MOVEMENT FROM PREVENTION PLANNING TO PREVENTION PROGRAM IMPLEMENTATION

by George Schmidt, Ph.D.
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It is my pleasure today to join with my colleagues from California, Iowa, and New Jersey to share our experiences in the effort to move from prevention planning to implementing programs that, hopefully, will result in the prevention of disabling conditions.

I am honored that the President's Committee on Mental Retardation selected the State of Florida as an exemplary state program. Our state has had a Centers for Disease Control cooperative agreement in place since 1988. The charge to Florida was, and is, "to build the state's capacity to prevent disabilities." In particular, we were to focus our efforts on reducing the incidence, prevalence, severity, and economic burden of developmental disabilities, head and spinal cord injuries, and related secondary conditions. For all of that award year we worked to:

A. Establish an Interagency Office of Disability Prevention (IODP).

B. Establish a volunteer advisory council to the project (Prevention of Disabilities Advisory Council).

C. Develop a state strategic plan for the prevention of disabilities.

D. Identify local, community-based projects to intervene in processes that cause disabilities.

   1. Programs selected on the basis of epidemiological analysis of available data.

   2. Development/utilization of local coalitions of citizens and/or existing interagency councils.

   3. Funding by Interagency Office of Disability Prevention (IODP) is seen as contributing to a multi-source package.

4. Funding is non-permanent, with an emphasis on developing primary or total state support over time for effective programs.

E. Foster the view of the Interagency Office of Disability Prevention as a "capacity builder" rather than an "empire builder."

1. Reduce the effect of "turf" issues.

2. Provide coordination services to participating agencies.

3. Provide technical assistance to other projects, advisory councils, agency program offices, and local communities.

During the Summer of 1989, the IODP and PODAC carried out a day-long, goal-setting exercise that served as a basis for the development of Florida's first strategic plan for the prevention of disabilities. The activities of the summer also yielded a "shared vision." This vision is embodied in a series of agreed-upon statements as follows:

1. Florida's future is her children and the opportunity for preventing adverse personal and societal outcomes is best achieved through prevention and early intervention programs.

2. Prevention is preferred to amelioration, and early intervention is preferred to later intervention, for both humanitarian and cost-effectiveness reasons.

3. Because of the complexity of prevention and early intervention activities, services, and programs, it is necessary to articulate the values upon which decisions will be made and to develop assumptions. Values and assumptions should be based on best practices, as delineated in the relevant literature, on needs, and on regional and local beliefs and customs.

4. The values, principles, and assumptions articulated through a review of the literature, opinions of national and state experts, and advisory groups of community-based parents and professionals reflect a shared vision that sets the stage for interagency and interdisciplinary programmatic efforts.

5. Establishment of formal mechanisms for interagency linkages with ongoing collaboration among a core group of state agencies.

6. Establishment of interagency coordination, as necessary, for data collection, analysis, and evaluation.

7. Utilization of local coalitions and local interagency citizen councils to reflect the resources and strengths of the community.

For the purposes of this session I will present to you a description of a program unique in concept, effective in action, but requiring additional support, both administratively and financially. Our objective for this prevention program is to "build the state's capacity."

OUTREACH CHILDBIRTH EDUCATION

"Preparation for Parenting"

Outcomes:

- Improved pre-natal care.
- Reduction in the incidence of low birth weight.
- Reduction in the number of unwanted second pregnancies.
- Improved literacy skills to enhance job opportunities.
- Improve ability to access systems of support and health care.

Family literacy and improved pregnancy outcomes among low-income, low-literacy groups are promoted through the Florida Outreach Childbirth Education Project. With a potential for serving more than 60,000 medically indigent families, the project is designed to attract hard-to-reach, expectant parents into Florida Adult and Community Education Centers for childbirth classes. In these classes, specially trained prenatal educators provide parents with unique learning experiences that promote family literacy as well as family health.

Many of the families served by the project face problems stemming from poverty, low literacy, underemployment, and poor health. Most lack the resources to cope with the additional stresses of pregnancy and parenthood. These and other complex factors combined with unhealthy lifestyles and behaviors, predispose pregnant women of this population to poor outcomes. Many are prone to preterm labor and birth, the leading cause of low birth weight (less than 5 1/2 pounds), one of Florida's worst health problems.

Low-birth-weight infants are at much higher risk of dying before their first birthday, suffer more from abuse and neglect, and are much more likely to experience learning disabilities and developmental delays than infants of normal weight. The poor start in life for low-birth-weight babies can have a significant, negative impact on their ability to become productive, literate members of society. Each year over 7.5 percent (about 12,000) of all Florida babies are low-birth-weight with a proportionately higher ratio to low-income mothers.

In 1982, the Florida Maternal and Infant Care Force cited the lack of childbirth education for low income women as one of the major problems contributing to poor pregnancy outcomes. Despite efforts to address this problem, the health education needs of lower socioeconomic childbearing families remain unfulfilled. This is unfortunate because pregnancy is a time when the majority of parents are most receptive to information related to their health and that of their unborn. Research shows childbirth education has a positive impact in these critical areas, among others:

- Nutritional habits.
- Avoidance of harmful substance such as tobacco, alcohol and drugs.
- Recognition of the danger signs of pregnancy.
- Use of automobile seat belts.
- Prenatal attachment to the infant.
- Responsible participation and consumerism in health care.
- Choice of infant feeding method.
- Early parenting skills.
- Locus of control and self esteem.
- Social support systems for the new parents.

Providing childbirth education through the adult education system has additional benefits. The adult who has not completed his or her basic education re-enters the system in a non-threatening situation and becomes accustomed to having perceived needs met in a classroom setting.

This may dispose the individual to participate in other adult education programs, especially completion of basic education. This participation can be actively encouraged as its correlation to parenting skills is stressed.

In 1989-90, the Florida Department of Education (DOE), formed a partnership with the Florida Department of Health and Rehabilitative Services (DHRS), the March of Dimes Birth Defects Foundation (MOD), the Coalition of Florida Childbirth

Educators (CFCE), and the Florida Healthy Mothers/Healthy Babies (HM/HB) Coalition to achieve the following program objectives:

1. Production of curricula for training of outreach childbirth educators and for teaching prenatal and childbirth classes for families with low literacy skills. These curricula are designed to meet the learning needs of poor readers, to broker adult and community education programs, and to encourage reading in the home.

2. Establishment of mechanism to provide childbirth classes to all low income families in Florida. Attracting low-income, low-literacy, expectant parents to childbirth classes is a highly effective outreach tool for other literacy and adult education programs. Outreach classes were begun at 33 new sites in 1989. A recent survey of County Public Health Units (CPHUs) in Florida revealed that approximately 15,000 of their maternity clients are being served by the outreach project.

3. Establishment of a mechanism for ongoing recruitment and training of outreach teachers. In 1989 alone, over 100 teachers were trained. Most completing the course are hospital and public health nurses who now teach in Adult and Community Educations Centers throughout the state.

4. Strengthening of the cooperative relationship between education and health organizations in Florida. At the state-level joint-funding between DOE and DHRS enabled the MOD, with support from CFCE, and HM/HB Coalition develop and implement the project at the local level.

5. Development of a program model which can be disseminated to other states.

For the 1990-91 fiscal year the Outreach Childbirth Education Project in cooperation with the Interagency Office of Disability Prevention developed the following goals and objectives:

GOAL #1

Expand the Outreach Childbirth Education Project to serve, at minimum, two thirds of the HRS County Public Health Unit (CPHU).

Objectives

1.1 Design and conduct a marketing campaign to promote increased attendance of OUTREACH classes among County Public Health Unit maternity clients and family members.

1.2 Recruit and train an additional 100 outreach teachers.

1.3 Establish outreach classes in 30 additional sites.

GOAL#2

Increase parental awareness of prevention programs designed to promote family literacy and health.

Objectives

2.1 Develop, produce, and pilot in a minimum of five sites, an early parenting curriculum which includes information to promote family literacy and health.

2.2 Conduct in-service education programs to familiarize all outreach teachers with new and ongoing family literacy and preventive health programs in Florida.

GOAL#3

Develop a plan for securing continuing support for the project.

Objectives

3.1 Establish an interagency steering committee to identify and secure resources needed to continue the project on an ongoing basis.

3.2 Investigate and report on potential private and public funding sources.

As noted above, development and implementation of the Outreach Childbirth Education Project was supported by a public - private partnership. Sustaining and expanding the project would require a different combination and a higher level of funding.

To meet the objectives established for 1990-91, the IODP assisted in establishing funding commitments from two programs within the Department of Health and Rehabilitative Services, the Department of Education, the University of Florida, the Developmental Disabilities Planning Council, the Florida Healthy Mothers, Healthy Babies Coalition, and the IODP itself.

In addition, successful negotiations were concluded which resulted in top level interagency agreements; mid-level memoranda of understanding; and at the operational level, contracts with providers.

Outreach Childbirth Education is underway for 1990-91. The program is being administered by the Healthy Mothers, Healthy Babies Coalition on the campus of the University of Florida. Funding commitments across five sources ranged from $26,000 to $40,000. Planning, management and evaluation are shared activities. Most importantly, the State of Florida increased its capacity to favorably impact the lives of tens of thousands of high-risk pregnant women.

IOWA COMMUNITY-BASED LOW BIRTH WEIGHT PREVENTION PILOT PROJECT

by Roger Chapman
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Let me begin by saying that the project I will describe this morning came from recommendations contained in the Iowa Disability Prevention Plan. We have had a plan in Iowa for about two years now. In many respects developing a plan is the easy part. Implementation is much more difficult.

As I understand the charge of this panel, we are to discuss movement from planning to implementation. Before I do that, it will be necessary for me to briefly provide an overview of Iowa's low-birth-weight prevention project. Funding comes from a grant awarded from the Centers for Disease Control. This grant creates an Office of Disability Prevention in the Department of Public Health and provides for community-based activity. Project objectives are accomplished by improving access to prenatal care; reducing substance abuse and other risk factors; and reducing teenage pregnancy.

Ottumwa, Iowa, was selected as the project site. Ottumwa is a city of 27,000 people located in southern Iowa. It was selected because:

1. It is typical of Iowa's agricultural-based communities;
2. Service providers have an established record of cooperation;
3. The target group was estimated to be of manageable size for a pilot project; and
4. Ottumwa is located in a poverty area.

The theoretical background of this project has it's roots in "primary health care." The core concept is that health services should not simply be delivered as a commodity, but should be an integral part of the community. As such, they should be owned and directed by the community itself, rather than imposed from the outside. The goal is to help foster community participation with the end result of autonomy, and the intervention becomes a self-sustaining part of the community infrastructure.

Having said all that, how does a recommendation contained in a plan become a reality in a community-based project? Early in the life of the project it was important to build its capacity at both the state and local levels to carry out project objectives. A local agency was identified to administer the program. This lead agency in Ottumwa also serves as the local MCH agency. A full-time coordinator was hired to oversee the project. On the state level, the capacity of the Office of Disability Prevention to provide technical assistance in support of project objectives was developed. This technical assistance is provided in the form of:

1. Data management;
2. Epidemiology;
3. Health promotion and education; and
4. community organization.

A relationship with the University of Iowa was also developed to provide surveillance support.

It is critical to the eventual success of any community-based project to foster grass roots support and encourage local networking. In order to do this, a local task force was appointed. The job of this task force was to provide guidance to the project in the application of a general prevention recommendation to a specific community problem. The membership of the task force included a cross-section of area professionals and lay people who could potentially be involved in prevention activity. Committee membership included:

1. A pediatrician,
2. An obstetrician,
3. A family planning representative,
4. An area education agency representative
5. An OB/GYN nurse practitioner,
6. A public health nurse,
7. A Department of Human Services Representative,
8. An alcohol/drug abuse counselor, and
9. A consumer

When asked what could be done locally, the task force chose to focus upon the prevention of adolescent and unwanted pregnancies. Specifically, the committee suggested educational programs in the public school system. The local high school had

long resisted any effort to include educational material focused on human sexuality in regular classes. However, this dramatically changed after a workshop was presented by the project that documented the local problem. A high school counselor attending this conference approached the project coordinator with a proposal for a class. After conferring with the project coordinator, the counselor approached the school superintendent with this idea. She received an enthusiastic endorsement. The coordinator then met with the high school counselors to work out logistical details. At this point considerable resistance was encountered. However, by then the question was who would do it and when, not if it would be done. The end result was a five-class curriculum entitled "Postponing Sexual Involvement" taught to all Ottumwa ninth graders in english class.

Next the school nurse on the task force approached the Alternative School Principal with the same idea. The Alternative School conducts classes for students who drop out of regular high school. The idea was also enthusiastically received. The result was two classes a week taught at the Ottumwa Alternative High School focused upon relationships and parenting.

The Pediatrician on the task force suggested another way to approach low birth weight prevention was to implement smoking cessation and teen prenatal classes. Both classes are currently being taught by the project.

The point of all this is to illustrate that local people who are committed to a prevention program are in the best position to make it work. By listening to local people and incorporating appropriate suggestions, the way is cleared for invested people to use existing linkages to meet program objectives.

Establishing local coalitions was an essential component in making the project work. Prior to the implementation of the project, active involvement was sought from the local medical society. Several discussions were held with local physicians to discuss the project and solicit their input. The project was presented as complementing, not competing with existing services. All too often new health-related programs require local health care providers to contribute time or other scarce resources. This project made no such request. In fact, analysis of project data would serve to enhance existing health services to area families.

Community awareness of the project was another essential component of moving from planning to implementation. At the beginning of the project, several local events were conducted to introduce the project to the community. An "open house" was attended by several area professionals. The resource library was of particular interest. A

"media meeting" was planned and conducted. Local media representatives (radio, T.V., newspaper) were invited to hear a panel of task force members talk about teen pregnancy in southern Iowa and project objectives. The data that was presented was supplied by field staff from the Office of Disability Prevention. The outcome of this was several newspaper feature articles and radio talk show appearances. The information presented was well-received because it involved local people discussing local problems.

Community awareness should be an ongoing process. In recognition of this, task force co-chairs have done a number of educational presentations to community groups discussing teenage pregnancy and project objectives. Apart from the obvious benefit of community awareness, such presentations continue to strengthen investment and ownership in the project by the presenters.

Public service announcements continue to publicize project activity. These include use of radio, T.V., and newspapers; posters in laundromats and on buses; project information stuffed in power bills; and printed on grocery sacks.

Keeping legislative decision makers informed about the project has been an absolute necessity. This has been done on both the Federal and state levels. An opportunity for interchange between local service providers and Federal representatives occurred last fall when government representatives came to Ottumwa to discuss local issues. These representatives included staff from the offices of Representative Leach and Senators Harkin and Grassley. The project was presented as a cooperative effort among Federal and state governments and local service providers. Two state legislators are members of the State Disability Prevention Advisory Board, and they receive regular progress reports and provide input into programmatic decisions.

The overall strategy of this project was to bring statewide resources to bear on a local problem. The Ottumwa project benefits from technical assistance provided by the Office of Disability Prevention and the University of Iowa. Examples of this technical assistance include the following:

> The category of low-birth-weight is a blending of preterm birth and poor fetal growth. When looking at growth retardation, one major contributing factor is birth defects. For the last five years, Iowa has been fortunate to have a statewide birth defects registry. The registry is operated under the direction of Dr. James Hanson from the University of Iowa. The registry has proved to be an extremely valuable surveillance mechanism to identify cases, trends, and analysis of potential risk factors contributing to low-birth-weight infants. Registry staff are currently examining the

relationship between water quality and low-birth-weight infants born in southern Iowa. Although those data are neither firm nor final, if a connection does exist, it would raise tantalizing possibilities for future prevention programs.

Beginning next month all women who deliver low-birth-weight infants in Ottumwa will be interviewed by project staff. This survey will examine health history, nutritional history, and exposure to teratogens.

This data will be managed and analyzed by the Office of Disability Prevention and the University of Iowa. The goal will be to identify barriers to care, or reasons for adverse outcomes. This survey should provide insight into utilization of prenatal care and financial and medical access barriers. The project will meet semi-annually with local physicians and service providers to present survey findings.

I would like to briefly mention one other piece of the technical assistance puzzle. All women delivering infants in Ottumwa will be offered a Maternal Serum Alphafetoprotein screening test. This test will be offered free of charge for those women not electing to have it done as a routine part of prenatal care. Those costs ($42/test) will be picked up by the Iowa Newborn Screening Program. The goal will be to identify high-risk pregnancies. Eventually, this may identify new categories of high-risk populations.

All these program components will help define the experience of women in the project area who have an adverse pregnancy outcome. These data, in turn, will be provided to local project staff. The obvious conclusion is that planning and implementation is a dynamic process requiring reliable surveillance and outcome data.

One final word about the on-going operation of a community-based project. It is critical to have a work plan that assigns specific responsibilities for objectives. Particularly if contract agencies are involved, it is important to formalize regular contact in order to monitor progress. In the Ottumwa project, this contact takes place a minimum of once a week. Staff from the Office of Disability Prevention also attend all task force meetings.

In summary, several things have assisted the Iowa low-birth-weight prevention project in movement from the ideas contained in a plan to the implementation of a community-based project. Those ideas include awareness, individual ownership, community ownership, and community involvement.

As for the future, we look forward to the full implementation of the disability prevention plan. We also look forward to the time when we are able to export the things we have learned in Ottumwa to the rest of our state.

GETTING THE LEAD OUT IN NEW JERSEY: AN EXAMPLE OF INTERAGENCY LEADERSHIP AND COOPERATION

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Prevention of mental retardation and other developmental disabilities is not an issue which can be "owned" by any single entity in state government. When working towards preventing mental retardation due to socioeconomic factors, getting rid of territorial and proprietary attitudes becomes a prerequisite for action.

New Jersey has moved beyond the planning stage into the implementation of efforts to address the causes of mental retardation associated with socioeconomic conditions. Some of these efforts are fairly well-developed and are in advanced stages of implementation. Others, even though implementation may have begun at the same time as the more advanced efforts, have been less successful. In trying to explain why these variances in implementation have arisen, I have observed differences in five underlying factors. These factors are:

1. Unchallenged, Recognizable Leadership
2. Consensus about the Social Good
3. Karma in Gear
4. Making Magic without Money
5. Suppression of Ego for Glory Sharing

My mission here this morning is to discuss each of these factors in relation to New Jersey's recent re-discovery of the widespread dangers of lead to our children. In so doing, I hope to dispel some myths as well, such as being unable to move from planning to implementation due to a lack of money, or the lack of cooperation being a barrier to action.

Unchallenged, Recognizable Leadership

New Jersey is fortunate to have enacted legislation in 1987 which established a Governor's Council on the Prevention of Mental Retardation and Developmental Disabilities and an accompanying administrative arm, the Office for Prevention of Mental Retardation and Developmental Disabilities (OPMRDD). These bodies were charged with the responsibilities of establishing public education programs, supporting research, identifying service gaps, and making recommendations about strengthening prevention efforts.

The Governor's Council consists of the commissioners or their designees of five state departments: Education, Health, Environmental Protection, Human Services, and the Public Advocate. Twenty-five citizens are appointed by the Governor, as well. It is important to note that the designees of the commissioners are all of high level positions--a deputy commissioner or a division director. Because the departmental representatives sit high in the hierarchy and influence policies, priority-setting and decision-making are possible.

The Governor's Council has identified 16 priority areas which are delineated in a table in our packets. Included is childhood lead poisoning prevention. In New Jersey, as is true in most other sates, prevention of lead poisoning has primarily been the responsibility of the Department of Health and, specifically, Maternal and Child Health (MCH) programs. However, decisions about the MCH block grant are discretionary, and at least in New Jersey, this has meant that competing needs have received a larger share of the pie. In addition, childhood lead poisoning prevention has relied mainly on a medical model and not upon primary prevention. Primary prevention in this case means resolution to broader social issues, such as housing abatement, environmental clean-up, public education, and accessible social services.

In actuality, lead poisoning prevention cannot be successful without interagency cooperation. To this end, the representative from the Department of Environmental Protection, Robert Tucker, Ph.D., organized the Interagency Lead Poisoning Prevention task force as a committee of the Governor's Council. The task force consists of representatives of the agencies listed above as well as the Department of Community Affairs, which is our housing agency. In some cases, several divisions from a department are represented, such as both Maternal and Child Health and Occupational Health.

In addition, community advocates and agencies are members. These include: the New Jersey Anti-Lead Coalition, the Head Start community, the New Jersey Coalition for

Prevention of Developmental Disabilities, the New Jersey University for Medicine and Dentistry, the New Jersey Public Health Officers Association, and others.

Because it mirrors the Governor's Council in its composition and has the authority to act on behalf of the council, the task force has much credibility and is the recognized leader in the collaborative efforts to remove lead from New Jersey. Of equal importance is the fact that all parts of the problem-- housing, environment, education, legal issues, and services--were recognized as part of the solution.

Consensus About the Social Good

I often hear that the lack of willingness to cooperate is a major barrier to resolving problems. In analyzing differences in the success of implementation of prevention programs, it is becoming evident that a major explanatory variable is the degree to which individuals agree about the value of reaching resolution. The lack of such a fundamental understanding seems to result in agency parochialism that is, individual identification with their agency's mission is more important than compromise and negotiation for the purpose of cooperation and resolution.

From its first meeting, the task force members explicitly put forth its philosophy: No person's life should be endangered or compromised due to lead poisoning. There was almost no discussion within the task force about the value of reaching resolution with respect to the lead problem.

This consensus has resulted in several important organizational outcomes which have matured over time. First, it is now recognized that the whole is greater than its parts, meaning that no single agency could resolve the problem on its own. During the earliest meetings, members of the task force, most of whom are in middle management, expressed their sense of feeling overwhelmed by the magnitude of the problem. By providing a forum through which individual members could be recognized for their contribution to the whole, a sense of achievement replaced feelings of frustration.

Second, it is now recognized that no single agency has a greater role in resolving the problem. The need for interdepartmental cooperation in defining achievable objectives encouraged understanding of the strengths and limits of each agency. Thus, while early discussions may have involved finger-pointing and casting blame, such debates are now tempered by more realistic expectations of the capabilities and the political realities of each department.

Finally, attempts to develop strategies which would move the issue of lead higher up on the political agenda were originally met with skepticism, as individual members were uncertain about the response of their commissioners. The task force resolved this issue by drafting an Action Agenda which assigned responsibility to each agency, specified roles for each commissioner, and recommended incremental approaches that each agency could implement. The Action Agenda was then endorsed by the Governor's Council and forwarded to the commissioners for their review and approval. This approach removed responsibility from the individual members and made the Governor's Council and task force the accountable agents. It has also had the benefit of insuring that the leadership from each department was in consensus about the value of lead poisoning prevention as a social good.

Karma in Gear

"Karma in Gear" means, very simply, good luck and good timing. Several important events occurred simultaneously with, or soon after, the task force was organized. First, the Office for Prevention of Mental Retardation and Developmental Disabilities was awarded a cooperative agreement from the Centers for Disease Control (CDC) for the Disability Prevention Program. Within the grant award was a small amount of money ($6,OOO) which was allocated to the task force to sponsor two forums.

Second, Congress enacted the Lead Contamination Act of 1988. This legislation authorized CDC to establish the Childhood Lead Poisoning Prevention Program. The program mandated three components: 1) expanded screening efforts; 2) plans for housing abatement; and 3) emphasis on primary prevention through public education.

Third, CDC announced that the blood lead level for children would be decreased to 15 ug/dl from 25 ug/dl. Changing the blood lead level has serious implications for defining the at-risk population, for focusing upon primary prevention, as well as for issues related to medical management, screening approaches, laboratory services, and costs.

Fourth, New Jersey is fortunate to have Federal and state legislators who are committed to lead poisoning prevention. It was certainly advantageous to have Senator Frank Lautenburg sit on the Appropriations Committee and for Senator Bill Bradley to be a leader in environmental legislation. In addition, a state legislator who is a scientist by training and chairs the Assembly's Environmental Committee, was willing to translate the task force's Action Agenda into a legislative package. Assemblyman Bob Smith has held public hearings on behalf of the task force regarding the bills. These bills are broad in nature and some are quite controversial, e.g., a proposed tax on all paint and allied paint products to be used to support expanded screening, public education, and other

activities and research, as well as a bill which assigns rebuttable responsibility to the allied paint industry for causing lead poisoning.

Fifth, the Office for Prevention had awarded a small, public education grant to a local Head Start agency. Concerned Parents for Head Start, through the work of Joan Luckhardt, Ph.D., produced a public education package regarding childhood lead poisoning and an accompanying video tape. The "Get the Lead Out" community discussion package provided a high-quality instrument to be used to inform citizens about the problem and has served as the basis for developing other primary prevention strategies.

Sixth, Herbert Needleman, M.D., published the findings in the *New England Journal of Medicine in January*, 1990, of a longitudinal study of the effects of low levels of lead upon human development. His findings documented that even small doses of this toxic element resulted in irreversible effects, including the inability to learn and other behavioral outcomes. These results gave an even greater credibility and sense of urgency to the task force's efforts.

And, finally, the United States Department of Housing and Urban Development (HUD) published its regulations regarding lead paint and abatement in the Federal Register in the spring, 1990. As luck would have it, a former state legislator and former commissioner of the Department of Community Affairs, was appointed to be the regional director of HUD. Anthony "Doc" Villane, a dentist by training, quickly understood the pervasiveness of lead in the housing stock and has been accessible to negotiate HUD's role in remediating the problem in New Jersey.

The advent of these elements served to elevate the status of prevention of lead poisoning within the overall political agenda within a short period of time. However, this karma would not have been of value had the task force not been positioned to capitalize on them.

Making Magic Without Money

I have been told that the total bill for the complete elimination of lead from New Jersey is greater than $50 billion--a sum which is bound to paralyze any group trying to wrestle with the issue. The lowering of the blood lead level for children means that virtually every child in New Jersey can be considered to be at risk. Over 60 percent of the housing stock in New Jersey was built before 1965 and over 80 percent by 1978 when the no-lead-in-paint legislation began to be enforced. New Jersey is the most densely populated state in the country and serves as a major transportation artery. The state is

connected to sister states on three sides by bridges that are legally painted and repaired with lead paint. Many of these bridges span densely populated areas.

New Jersey is the second most industrialized state in the nation. Many of its industries have relied upon lead. In addition, New Jersey has large agricultural areas in which farm vehicles are still legally fuelled by leaded gasoline. As a result, the lead content found in soil and water due to both industry and agriculture is high.

A total of $6,000 in cash is hardly what one would call a great investment into raising policy-makers and the general public's awareness about the problems of lead in New Jersey. Yet, in both 1989 and 1990, the task force used this amount of funds each year to sponsor conferences. As the word spread about the lead problems, other agencies and individuals contributed to these public education efforts. However, even with in-kind contributions, the amount of cash-in-hand was never very much.

The task force has been able to take action because it has used its funds wisely. It first sponsored a forum for policy makers and legislators. The forum provided a status report about lead programs as well as educating decision-makers about the implications of lowering the blood lead levels. This had the effect of putting decision-makers on notice: they could take actions to prevent lead poisoning voluntarily, or they could wait until actions were imposed upon them when the blood level was lowered.

Second, the task force sought to build a broad constituency by sponsoring large, public education conferences. These conference focused on all the issues associated with lead poisoning--medical, educational, legal, parental concerns, housing, environmental, and occupational. While presenters emphasized that poor children who resided in the inner cities were still considered to be most at risk, the implications of the low levels of lead poisoning to all children were also made clear. Thus, the audience was broadly defined and representative of many interests. Finally, members of the task force published articles in relevant journals, participated in cable television and radio shows, and were interviewed for newspaper articles. These efforts resulted in the dissemination of information to broad audiences at no cost.

These small investments of cash and large investments of time are beginning to pay off. Because the state, through the work of the task force, has begun to make major strides in the elimination of lead from the environment. New Jersey was awarded a Childhood Lead Poisoning Prevention grant from the Centers for Disease Control (CDC).

However, the task force also expects to reap additional awards from its efforts. For example, it is likely that HUD funds will be made available to be used to abate houses. While there is currently much resistance in New Jersey to imposing new taxes, it is also quite probable that the legislative lead package will be enacted, thus resulting in a tax on the paint manufacturers' receipts. Finally, some private sector industries are beginning to express their interest in joining the "Get the Lead Out" campaign.

Suppression of Ego for Glory Sharing

> "The poor ego has a still harder time of it; it has to serve three harsh masters, and has to do its best to reconcile the claims and demands of all three. The three tyrants are the external world, the superego and the id" (Freud).

A major concern in working to resolve the ills of the world pertains to who gets the credit. For those of you who work in state government, you will understand when I say that suppressing egos is a difficult task indeed, even when there is consensus about a social good. The task force, too, has had three tyrants which has required it to engage in delicate balancing acts.

The first is our external world. The task force was built upon the philosophy of inclusion and representativeness. However, as the task force gained in influence, two phenomena began to occur. One, there was a "jump on the bandwagon" phenomenon. This group tended to include individuals who had originally declined to be a member of the task force. The second phenomenon pertained to those who "came out of the woodwork." This group included individuals whose interest in preventing lead poisoning became apparent around the time that CDC announced the availability of funds and recognized that the task force had become the coordinating agent for the state.

Our second tyrant, the "superego", pertained to the commissioners and other political figures. It was necessary to carve out a public position for each department leader without imposing a hierarchy of importance. In this regard, New Jersey has been quite fortunate to have commissioners who recognize the importance of collaboration, without any single department laying claim to the most credit. By using the Action Agenda, which clearly delineated individual as well as interdependent roles for each agency, the commissioners were able to be recognized for their cooperation and their department's contribution.

Finally, our last tyrant, the "id", was the task force itself. Having worked diligently for two years, it was difficult at various points not to grandstand. Members of the task force resolved this issue in a relatively simple fashion: at all public occasions, the commissioners, legislators, and others were given the recognition and credit. Afterwards, we all went out to celebrate and pat ourselves on the back in private.

CALIFORNIA--ADDRESSING THE NEEDS OF A CHANGING SOCIETY

by Raymond Peterson, M.D.
Director
San Diego Regional Center
San Diego, California

"Addressing the Needs of a Changing Society" is essential when you are developing a plan to prevent mental retardation and related disabilities associated with socioeconomic conditions. After a brief overview on prevention planning, referencing the "PCMR Guide for State Planning" developed by Dr. James O. Cleveland and me in 1987, I will present data from our California experience which provides a direction on where to place prevention efforts to make a difference in addressing the "New Morbidity." I will also share an example of a successful program we have used in San Diego to target an underserved population in order to provide intervention, using known and accepted prevention strategies.

I expect and hope that you are all familiar with the "PCMR Guide for State Planning: For the Prevention of Mental Retardation and Related Disabilities". The essential components to be considered in any planning effort are listed.

- Socioeconomic Factors
- Prenatal and Perinatal Care
- Genetic Factors
- Infants At-Risk
- Environmental Factors
- Special Considerations
- Education/Public Awareness
- Personnel Development
- Data Collection/Evaluation
- Research

The significance of the fact that the socioeconomic issues are listed first is that these issues interrelate with all of the other components, such as prenatal care, education, accidents, immunizations, etc. Information that I will share also emphasizes the importance of data collection and evaluation in targeting populations at risk.

The delivery system for services for persons with developmental disabilities and for prevention in California is coordinated through a regional center system. California, with a population of more than 25 million persons, is divided into 13 planning areas served by 21 regional centers. One regional center may serve many counties, and 7 regional centers serve the 9 million persons who live in Los Angeles county. the San Diego Regional Center, of which I am Executive Director, serves the two most southern counties bordering Mexico, with a population of approximately 2.6 million persons and an active case load of more than nine thousand.

The law in California, the Lanterman Developmental Disabilities Services Act, defines services to be provided for persons with mental retardation and other developmental disabilities. The law also provides a commitment by the state to the prevention of developmental disabilities and an entitlement to prevention services. The Regional Center System is a partnership between state government, 21 nonprofit corporations that operate the regional centers, and community services provided by nonprofit, profit, and governmental agencies and individuals.

The Association of Regional Center Agencies (ARCA) represents the 21 contracting agencies and regional centers, and has within its structure a committee system to address issues facing regional center consumers and the service delivery system. ARCA's Prevention Committee, has three active subcommittees which address prevention activities in California. These subcommittees are: 1) Persons at Risk of Parenting a Child with a Developmental Disability (genetics); 2) Infants at Risk of Becoming Developmentally Disabled; and 3) Public Information and Public Awareness. The most important is Public Information/Public Awareness, because, no matter how sophisticated we are from a scientific standpoint, we will have little impact on reducing the incidence of mental retardation or reducing mortality or morbidity, if the public or consumer is not informed and does not have access to what is known to assist in assuring a healthy and productive life.

Public awareness activities include distribution of materials developed by the Committee about selected prevention topics to each of the 21 regional centers, so that information can be disseminated to persons in all of the 58 counties in California. Public media is used and is coordinated between the regional centers and the State Department of Developmental Services. The topics that are targeted for this year are:

- Substance Abuse and Life Styles
- Prevention of Childhood Injury
- Near-Drowning

- Pediatrics AIDS
- Lead Poisoning

The Prevention committee as a whole and individuals have also participated in the development of a new plan for the prevention of childhood disability in California. "Prevention 1995" will build on the strengths of the previous state plan, "Prevention 1990: California's Future". This plan was developed through the guidance of Dr. Mary Lu Hickman, who has arranged the display from California for this meeting. Available handout include an overview and outline of "Prevention 1995" and a status summary of the accomplishments in meeting the objectives of the Prevention 1990 plan. A number of brochures on prevention, in English, Spanish, and Southeast Asian dialects, developed by the San Diego Regional Center, are available for those who are interested.

A Childhood Disability Task Force has been appointed by the Health and Welfare Agency to provide input and assist in developing the new five-year childhood disability prevention plan. One of the first tasks has been to evaluate what has been accomplished during the past five years. This will be particularity important as our new governor, Pete Wilson, looking to California's future, has presented his first initiative, to focus on prevention with accessible prenatal care.

One of the major activities of the task force is to determine where we can make the biggest impact through prevention activities. Where do you get the biggest bang for the buck? What areas do you target? As Dr. Moser pointed out in his presentation yesterday, our target is changing; and as Dr. Alexander and others pointed out, our tools and our armament are also changing. We can make a difference immediately through such activities as widespread immunization to prevent a recurrence of our recent measles epidemic, and widespread usage of the recently-approved hemophilus influenza vaccine to prevent the devastating effects of meningitis in infants and children.

The importance of data collection is seen in the information collected on risk factors identified for persons with developmental disabilities served in California Regional Center System (N=93,767 clients). The data is 74 percent complete, and there is duplication because some clients have numerous risk factors. You will note that low-birth-weight/prematurity is the most frequent risk factor identified (8.53 percent), followed by a family history of mental retardation (5.57 percent), material age greater than 35 (5.15 percent), psycho-social factors (3.55 percent), and accidents (3.04 percent). [Figure 1]

Figure 2 provides information regarding risk factors identified for 22,663 high-risk infants served through the regional centers during the five and one-half years from July 1985 through December 1990. This information is complete, but risk factors may be duplicated. You will note that approximately one-third of the infants were premature (32.5 percent). More than 25 percent had very low-birth-weight (25.5 percent), and more than 20 percent had a history of maternal chemical exposure/abuse. The numbers of infants who have been exposed to drugs during pregnancy continues to grow and is a major factor in the "New Morbidity".

There are significant population changes seen in many parts of the United States. Figure 3 shows the growth and ethnic changes in Los Angeles County between 1970 and 1988. The population increase during the 18-year period, shows the population changing from 6.9 million to 8.7 million. This is the result of migration of persons to the warmer climate, a large immigration of persons entering the United States from throughout the world, and a high birth rate. Most significant is the ethnic change, with the Hispanic/Latino and Asian populations showing the greatest growth and percentages of ethnic groups changing dramatically. In 1970, 70.9 percent were identified as Anglo, and 14.9 percent were Hispanic; in 1988, 46.3 percent were Anglo and 34.5 percent were Hispanic; Asian/others growing from 3.4 percent to 9.5 percent during the same period.

Data on new clients with developmental disabilities entering the regional center system during the past three years (17,918 clients) shows a significantly increased percentage of persons who were premature/low-birth-weight. 13.8 percent of all persons entering were listed as premature/low birth weight; however, 21.23 percent of children 0-3 had a history of prematurity. Psychosocial factors were present in 6.8 percent; child abuse was noted in 5.56 percent maternal drug or alcohol abuse in 4.92 percent; and accidents in 4.55 percent. [Figure 4.]

This information reflects the problems we have with the "New Morbidity". Regardless of the specific cause, and there are usually multiple factors, we have identified the targets and must develop intervention strategies to reduce the incidence and ameliorate the effects of socioeconomic conditions that contribute to childhood disability.

I would like now to briefly focus on programs in the San Diego area, funded as SPRANS (Special Projects of Regional and National Significance) grants by the Bureau of Maternal and Child Health, to assist targeted populations to access services.

First, let me describe the area and population that we serve. San Diego and Imperial Counties are the two most southern counties in California, bordered by Mexico on the south, Arizona on the east, and Pacific Ocean on the west. The Mexican-

American border crossing at Tijuana is the busiest in the world. The population of the two-county area is more than 2.5 million. The city of San Diego, with a population of more than 1 million persons is the sixth largest city in the United States. Many people think of San Diego as being a small navy town, with warm beaches, many recreational opportunities, and a world-famous zoo. (Dr. Albert Anderson, PCMR Vice Chairman, is president of the zoo, a full-time job, in addition to all of the other things that he does.) There are a number of world-famous universities, including the University of California-San Diego, which has an outstanding medical school. The area is generally considered to be urban; however, the majority of San Diego County residents live in rural areas. According to the 1980 census, 14 percent of the population in San Diego County was Hispanic/Latino and 6 percent were Southeast Asian, with more than 60,000 refugees. Imperial County has approximately 100,000 residents in a geographic area approximately the same size as San Diego County. The per capita income in Imperial County is the lowest of all of the 58 California counties, and more than 50 percent of the residents use Spanish as their primary language. The area is largely agricultural with large farms. There are many problems in dealing with the cultural diversity and the services that are needed.

The San Diego Regional Center developed a program to provide genetic services in our two-county area in 1972. This has resulted in a high standard of care for the provision of services including genetic counseling, prenatal diagnosis, etc. In reviewing our data, however, we identified that the population being served was not representative of our communities. We had low utilization by minority groups, especially those who lived in rural areas, and who were non-English speaking. Through the SPRANS grant we targeted these populations, with outreach to providers and to consumers, using culturally-sensitive educational materials presented in the consumers' primary language. Although we were not able to find trained bilingual and bicultural genetic counselors, we were able recruit and hire two capable professionals who we were able train in genetics and in counseling techniques. During the three-year project, we observed a case load increase of 35 percent, from 557 to 754, which could be explained by the addition of the two staff counselors. [Figure 5]

The change in ethnic composition was striking. The number of persons identified as Anglo remained approximately the same during this three-year period; however, the number of Latinos increased from 81 to 231, and the number of Asians from 10 to 82. The percentage of Latino clients increased by more than 200 percent, and the percentage of Southeast Asian clients increased by 150 percent. [Figure 6] The non-English-speaking clients, prior to this project, has increased to 34 percent (28 percent Spanish, 6 percent Southeast Asian) 240 persons (177 Spanish, 65 Southeast Asian), or one-third of the persons served were non-English speaking.

Project staff identified professionals who were providing services, including 16 health clinics in the two-county area that were serving low-socioeconomic families and offered in-service training in genetics and prenatal care. Bilingual providers were contacted to explain the services provided by the project. Efforts were made to reach families throughout our region, and a toll-free telephone number was established to respond to inquiries in English, Spanish and Vietnamese. A poster was developed and distributed to advertise the multilingual, multicultural genetic services and the toll-free number.

Genetic counseling was provided within the community, with follow-up at the person's home. Pictorial materials were written to assist in providing information. Basic informational pamphlets, explaining prenatal diagnosis, Maternal Serum Alpha Feto Protein (MSAFP) screening, and genetic counseling, were developed in English, Spanish, Vietnamese and Laotian. These were shared within the community to increase knowledge about genetic topics. Newspapers, health fairs, and conferences were used to heighten awareness about the project.

This project demonstrated that individuals/families in Latino and Southeast Asian cultures are receptive to and will utilize genetic counseling information and services when such information and services are made accessible to them. Since the project terminated, we have maintained the two bilingual positions (Spanish and Vietnamese) to assure that services will continue to be accessible to these populations. We have also expanded prevention services to address the needs of Southeast Asian refugees in our community, who are faced with cultural and language barriers that limit the use of community services. the model for the Southeast Asian Developmental Disabilities Project (SEADD) uses bilingual/bicultural case managers from the Vietnamese, Cambodian, Laotian, and among communities, who have been trained to assist families to obtain services for high-risk infants, and genetic services. By targeting this population and providing outreach to families who have immigrated to the United States, we have assisted individuals to assimilate into the community, and to obtain services as a part of our efforts to prevent or ameliorate childhood disabling conditions. This has been a very successful and exciting project; however, because of time constraints it will be necessary to provide additional information on the Southeast Asian Developmental Disabilities project on another day.

Figure 1
RISK FACTORS

[from CDER (duplicated) - 93,767 clients (74% complete)]

Low Birth Weight/Prematurity		8.53%
Family History of Mental Retardation		5.57%
Maternal Age Greater than 35		5.15%
Psychosocial		3.55%
Accident		
Near Drowning	0.34%	
Automobile	1.01%	
Other Vehicles	0.25%	
Other Type of Accident	1.44%	
Child Abuse/Neglect		2.76%
Drug/Alcohol Abuse		2.01%
Teenage Pregnancy		1.84%
Environmental Toxin		0.25%
Other Causes		5.64%

California Department of Developmental Disabilities
Office of Planning and Policy Development - January 1991

Figure 2
RISK FACTORS
July 1985 - December 1990

[High-Risk Infants (duplicated) - 22,663 Infants]

Prematurity	32.5%
Very Low Birth Weight	25.5%
Significantly SGA	8.0%
Serious Biomedical Insult	10.0%
Multiple Congenital Anomalies	10.8%
Maternal Chemical Exposure/Abuse	20.4%
Poor Parent/Infant Attachment	7.1%
Family History of Abuse/Neglect	9.3%
Parent Medical/Mental Condition	10.8%
Other Social/Environmental	7.6%

California Department of Developmental Disabilities
Office of Planning and Policy Development - January 1991

Figure 3
POPULATION BY ETHNICITY
LOS ANGELES COUNTY: 1970 AND 1988*

	Persons (thousands)		Percent	
	1970	1988	1970	1988
Anglo	4,885	4,022	70.9	46.3
Black	747	851	10.8	9.8
Hispanic	1,024	2,998	14.9	34.5
Asian and Others	234	823		
Total Population	6,890	8,694		

*Source: The Widening Divide: Income Inequality and Poverty in Los Angeles. The Research Group on the Los Angeles Economy, Los Angeles, California, June 1989.

Figure 4
RISK FACTORS
New Regional Center Clients
January 1988 - December 1990

[from CDER data (duplicated) - 17,918 clients]

		88/90
Low Birth Weight/Prematurity		13.8
(0-3 years)	21.23%	
Family History of Mental Retardation		9.39
Maternal Age Greater than 35		8.43
(0-3 years)	10.56%	
(4-17 years)	6.41%	
Psychosocial		6.88
(0-3 years)	4.98%	
(4-17 years)	9.17%	
Accident		4.55
Near Drowning	0.5%	
Automobile	1.58%	
Other Vehicle	0.42%	
Other Type Accident	2.05%	
Child Abuse		5.56
(0-3 years)	4.68%	
(4-17 years)	7.61%	
Drug/Alcohol Abuse		4.92
(0-3 years)	7.17%	
(4-17 years)	4.8%	
Teenage Pregnancy		3.42
(0-3 years)	3.64%	
(4-17 years)	4.16%	
Environmental Toxins		0.39
Other Causes		8.78

California Department of Developmental Disabilities
Office of Planning and Policy Development - January 1991

Figure 5
(Peterson)

Number of Genetic Counseling Cases Opened by Year

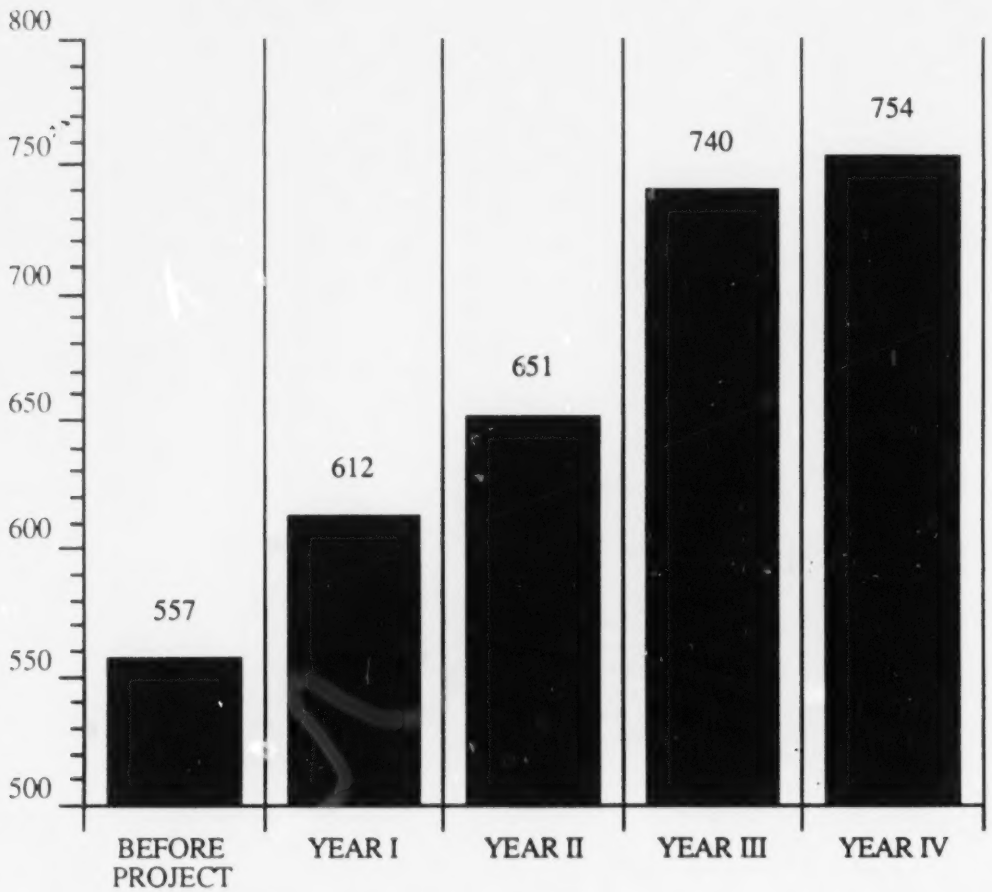


Figure 6
(Peterson)

Ethnicity of Clients by Year

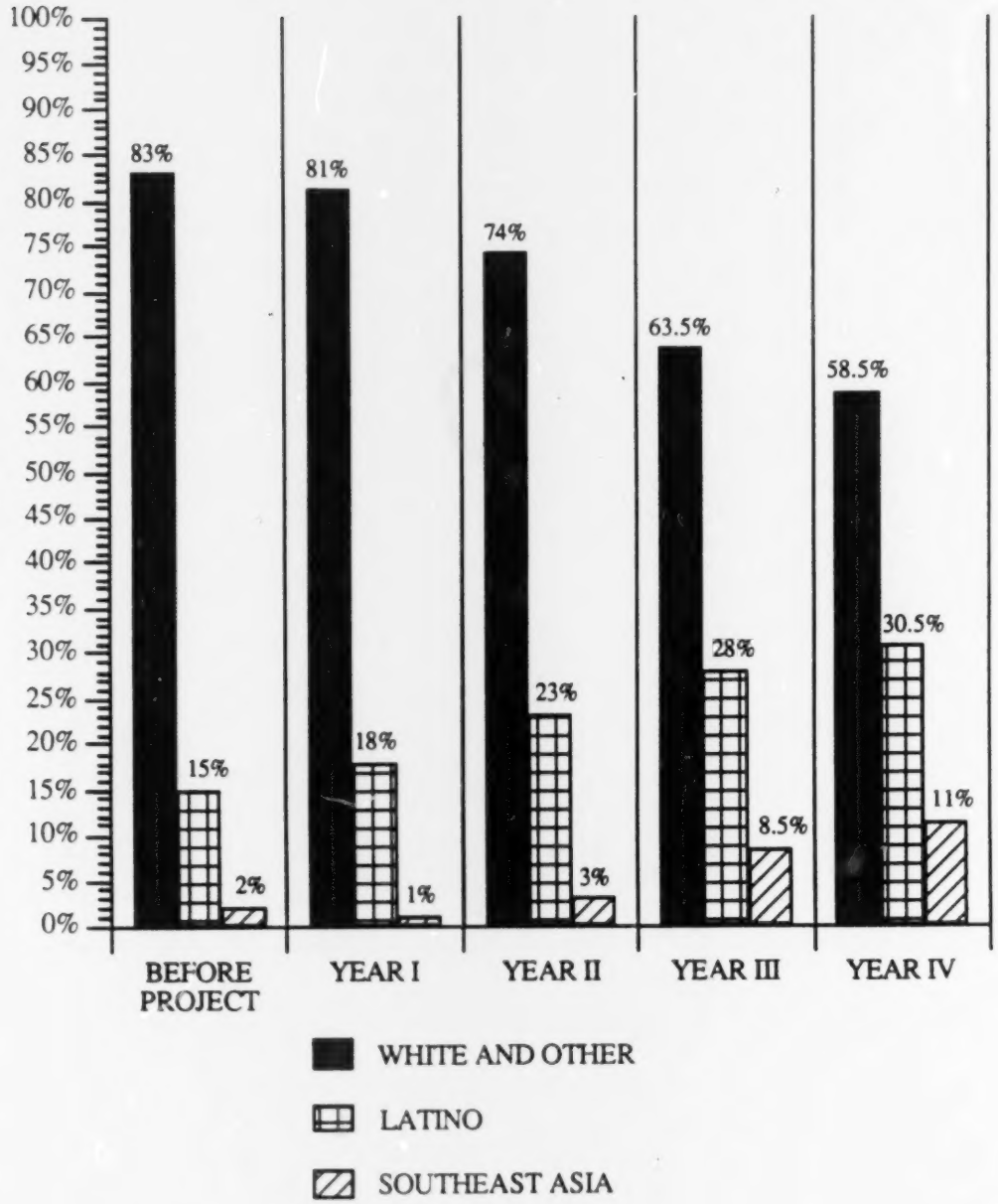
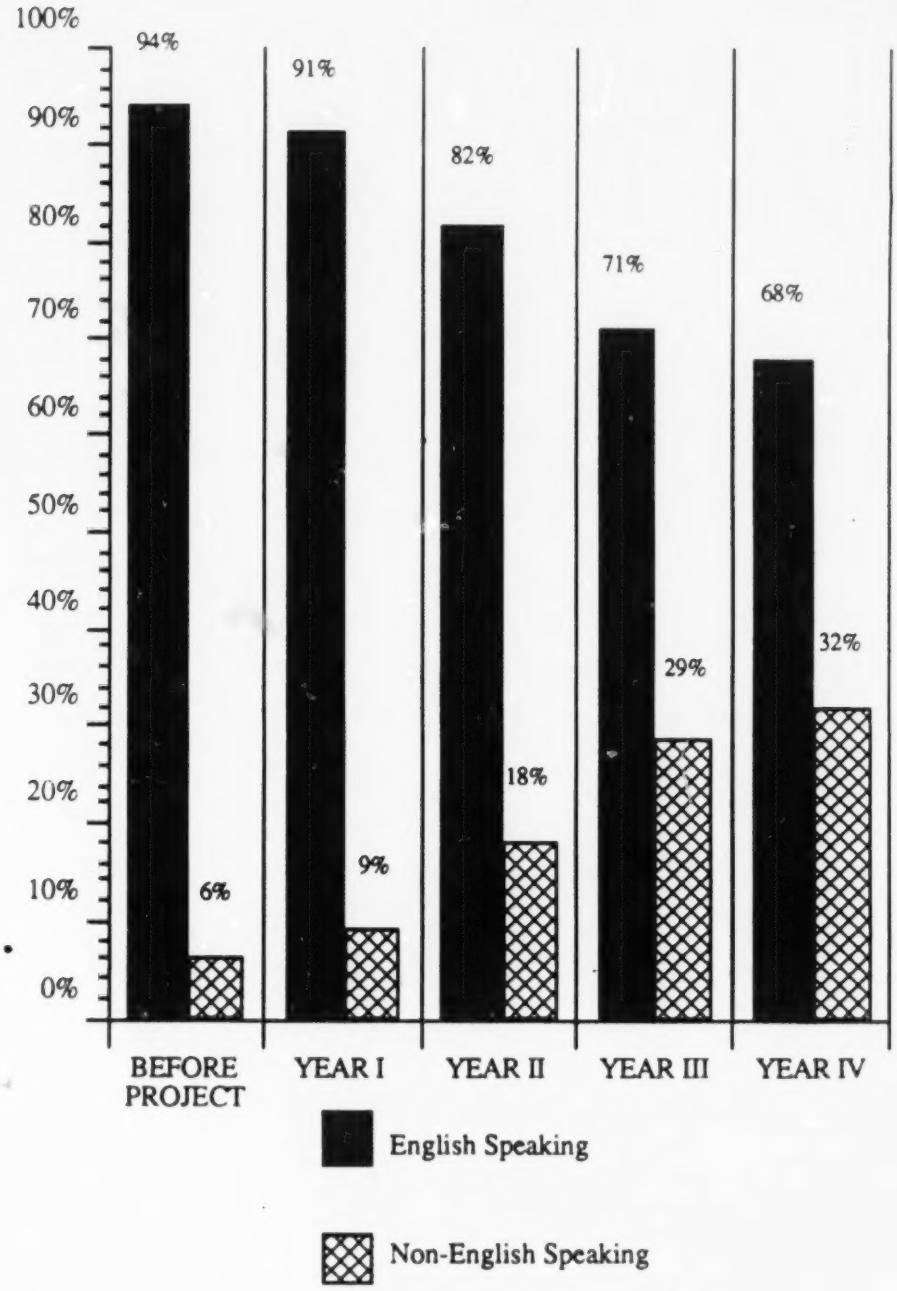


Figure 7
(Peterson)

Percent of Non-English Speaking Clients by Year



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ARTICLE 8
(Peterson)

World/Nation

Health care disarray hurts kids

Retardation not treated properly, report declares

Knight-Ridder News Service

Youngsters from poor families are more likely to be mentally retarded and suffer lifelong learning disabilities because the nation's system of preventing those illnesses for the poor is in disarray, a report to the President has concluded.

The report, which is to be presented to the President's Committee on Mental Retardation later this week, challenges federal and state governments to improve access to adequate health care for all.

"Our health-care system ... is highly discriminatory against children - particularly minority and poor children - and should be restructured," said Albert A. Baumeister, one of the authors of the reports.

The 220-page report by Baumeister, a Vanderbilt University professor and researcher, and three colleagues seeks to link the prevention of mental retardation and developmental disabilities with an array of other health issues related to unfavorable socioeconomic conditions, including infant mortality, low birth weight, pediatric AIDS and fetal alcohol syndrome.

"Ours is a piecemeal system of public health practice that does not quickly and reliably connect with those who are at greatest risk" for a host of interrelated health problems, including mental retardation, the report says. "By recent comparison with other Western nations, our public health services are inadequate and poorly organized for addressing the health needs of the poor, minority groups and families at risk."

The report opens by quoting Louis W. Sullivan, secretary of health and human services - "Good health must be an equal opportunity, available to all Americans" - and goes on to detail countless connections between poverty and inadequate health care.

Among its recommendations is the expansion of Medicaid to make prenatal care available to all low-income, high-risk women. Under the present system, pregnancy must occur and be diagnosed before the process of Medicaid enrollment can begin, thus discouraging early prenatal care, the report says.

The report also contains a section on early-intervention strategies gleaned from nine states that responded to a request for mental-retardation prevention plans. According to Baumeister, Virginia, New Jersey, New York, Iowa, Florida and California have the most sophisticated plans.

The presidential committee, established by Lyndon B. Johnson in 1966, oversees the national effort to prevent mental retardation and related disabilities. In 1971, the committee established two goals: to reduce by half the incidence of mental retardation during the 20th century, and to avert mental disabilities linked to poor socioeconomic conditions.

According to the report, the fundamental difficulty in achieving those goals is "the failure to implement comprehensive and socially relevant policies that would apply existing knowledge to existing problems. "It would only be fair to assert that, at the present, the effort to prevent mental retardation and other developmental disabilities is in disarray," the report says.

Among the obstacles to achieving an ideal system, it says, are budgetary constraints that result in cutbacks of necessary programs; fragmented prevention-oriented services at the local, state and federal levels; lack of a national health-care program to address the needs of all citizens, and the failure to place prevention at the top of the national agenda.

According to Baumeister, the lag in services cannot be explained by a lack of resources. The United States spends more than any other nation - about 12 percent of its gross national product - on health care, he said in the interview, but infant mortality statistics are such that "it is better to be born, if you're black, in Pakistan or somewhere like that" than in the United States.

Baumeister acknowledged that certain of the report's recommendations, such as those regarding family planning clinics and counseling, might meet with political resistance, but, he said, "as many (recommendations) as we're making, if they accept 10 percent of them, I will consider it a success."

CLOSING PLENARY SESSION

February 7, 1991

MODERATOR: Fred J. Krause
Director
Rehabilitation and Health Services
Partners of the Americas
Washington, D.C.

Work Group Reports
Work Group Recommendations

Summary of Work Group Reports

SUMMARY OF WORK GROUP REPORTS AND RECOMMENDATIONS

Work Group I: Application of the "New Morbidity" Model to Comprehensive State Planning

Alfred Baumeister, Ph.D.

Key Issues

Lack of a child care system.

Changing demographics that characterize the work force--working mothers of infants and children.

Absence of a state planning strategy that improves services to all children.

Access to services that provide the basics for all families.

Lack of a valid and reliable national database system to track prevention indicators and provide information regarding the extent to which prevention efforts are successful.

Recommendations

Extend public education with families downward, beginning at birth and using the home visitor concept.

Initiate formal schooling at three years of age, with appropriate fiscal support from the Social Security Fund tracking this system.

Get funds for educational programs and services into the hands of people who need them, using a "children's allowance model".

Professionalize the occupation of child care provision into a career ladder concept, starting at the vocational level and working through advancing levels of proficiency until the Bachelor of Arts level of competence is reached.

Make child care an integral part of the American public school system.

Prevention planners at the state level should determine what programs and services are needed and wanted, and outline a strategy for addressing the assessed needs, based on analysis of the peculiar circumstances that characterize the state.

Involve private industry in state planning efforts and focus on productivity.

Make more effective use of the media by capitalizing on media capability to portray unmet needs and address solutions to these needs.

Establish alliances with governors and legislators at the state and national level who have demonstrated interest in mental retardation and related disabilities, and make use of their influence and visibility to address the needs of children, mothers and families.

Actively advocate for full access to services for all "at-risk" groups, but particularly for minorities and socioeconomically disadvantaged populations.

Institute a national database to track indicators of the adequacy of efforts to reduce the incidence and ameliorate the effects of mental retardation and related disabilities; indicators including prenatal care, low birth weight, and immunizations.

Work Group II: The Role of State and Federal Government in Facilitating Comprehensive State Planning

Edward P. Burke

Key Issues

Disparity in formula funding and planning monies between poverty areas and urban versus rural areas.

Fragmentation between Federal programs, state programs, and local/community programs.

The dilemma of the message that primary prevention sends to some people with mental retardation and related disabilities, that somehow they are not valuable.

Limited use of generic or other human service programs to address the socioeconomic conditions that contribute to developmental disabilities.

Reduced access to programs and services, caused by the attachment of too many "add-ons" to governmental programs at the local level.

Attitudinal barriers to comprehensive planning and service delivery at the local level.

Recommendations

Reexamine the ways in which we define rural-versus urban areas when decisions relative to formula funding and planning monies are being made.

Encourage and support the establishment of more Federal, state and local interagency alliances around topical issues.

Involve more people with disabilities in planning efforts, and invite their input regarding the direction in which prevention planning should be focused.

Improve the process by which people access services, using "consumer-friendly" strategies that reduce the possibility that consumers will see the process itself as a barrier.

Encourage and utilize family-centered approaches to service delivery, involving fathers, extended family members, and "significant others" in the process.

Identify and address attitudinal barriers to the comprehensive planning and delivery of services.

Work Group III: Strategies for Addressing Epidemiological Needs, Concerns and Interests

Godfrey Oakley, M. D.

Key Issues

Failure to use epidemiology as a tool for facilitating success in reducing incidence and prevalence rates in mental retardation and related disabilities.

Lack of appreciation, on the part of people responsible for appropriating and allocating funds, for the value and role of epidemiology in the national effort to prevent disabilities.

The value of intervention research in determining how to prevent primary disabilities and how to prevent secondary conditions that might occur in people who already have a developmental disability.

The difficulty experienced in attempting to identify children at risk.

Recommendations

Continue research efforts at the national, state and local level into known and unknown etiological factors in mental retardation and related disabilities.

Encourage interdisciplinary efforts to outline and implement more effective methods for identifying children "at-risk".

Establish a network of epidemiology developmental disability centers to: a) conduct etiologic and intervention research; b) address developmental disabilities and the secondary complications in persons with these disabilities; c) develop methods that will be useful for surveillance, keeping a "scorecard", improved implementation of Public Law 99-457, Child Find, and routine identification of children "at-risk" in ways that facilitate comparisons between the states; d) engage in health services research related to comprehensive care and services for children with developmental disabilities; and e) provide training for persons interested in epidemiology.

Use the surveillance data collected and analyzed by the epidemiology developmental disability centers to develop "the gold standard", or a method by which we count every child affected as opposed to a method wherein a less valid and reliable sampling scheme might be used because of cost considerations.

Work Group IV: Successful Planning of Constituency Group, Interagency, and/or Intra-agency Initiatives that Support Comprehensive State Planning

Sonya Oppenheimer, M.D.

Key Issues

The question of whether prevention coalitions should focus on broad-based issues or limit their scope to more narrowly defined issues.

The extent to which parents should be invited to serve on prevention coalitions and governmental panels that review applications for grants.

The extent to which persons working in the field of developmental disabilities are trained to address the needs of substance abusers and children who are victimized by parental substance abuse.

The placement of an Office of Prevention within a state service delivery system, and the most appropriate naming of such an office.

Recommendations

Invite and support strong involvement of parents on prevention coalitions.

Use peer mentoring to encourage the involvement of individuals who represent socioeconomically disadvantaged populations on prevention coalitions at the local, state, and national levels.

Expand prevention coalitions to include persons interested or involved in any aspect of prevention, and to be characterized by an interdisciplinary, inter-generational, multicultural membership.

Invite representatives of agencies that serve persons with substance abuse or related problems to serve on local, state, and national prevention coalitions.

Encourage the establishment and maintenance of a state Office of Prevention that it independent rather than part of the institutionalized bureaucracy within the state.

Work Group V: Practical Approaches to the Formation and Endorsement of National Prevention Policy

Allen Crocker, M.D.

Key Issues

How are policy recommendations formulated?

Who can make policy recommendations?

For whom are policy recommendations crafted?

How are policy recommendations given clout?

Will policy recommendations alter the outcome of national prevention policy?

Recommendations

Support communities in such areas as employment, housing, nutrition, safety and environment.

Make mandatory the use of meaningful curricula for the school-based education in preparation for parenthood, beginning at the late elementary level and continuing through the high school level.

Establish a national advisory committee, heavily consumer driven, and a Federal interagency council; both recommended by the Institute of Medicine in the publication, Disability in America...Toward a National Agenda for Prevention.

Make health care accessible to all Americans, and establish universal health insurance.

Emphasize continuing support for research in the mechanisms of developmental disabilities, an area where a knowledge gap has limited our ability to be effective promoters of good prevention.

APPENDICES

APPENDIX A	PROGRAM AGENDA
APPENDIX B	EXHIBITORS
APPENDIX C	PROGRAM PARTICIPANTS
APPENDIX D	ATTENDEES
APPENDIX E	PLANNING COMMITTEE
APPENDIX F	PCMR MEMBERS AND STAFF

APPENDIX A

Summit on the National Effort to Prevent Mental Retardation and Related Disabilities

PROGRAM AGENDA

APPENDIX A
PROGRAM AGENDA

February 5-7, 1991

Omni Shoreham Hotel
2500 Connecticut Avenue, NW
Washington, DC 20008

STATEMENT OF PURPOSE

The purpose of this Summit is to assess the adequacy of the national effort to prevent mental retardation and related disabilities, and chart the course for future strategies to reduce the incidence and ameliorate the effects of socioeconomic conditions as etiological contributants to these disabilities.

The pre-Summit reception will provide a forum for informal deliberation and showcasing of the efforts of state and territorial representatives to develop and implement comprehensive plans for minimizing the occurrence of mental retardation and related disabilities in children.

"Themes" to be addressed by the Summit participants are:

- Preventing the "New Morbidity"
- Conditions that Negatively Affect Mothers and Children
- Improved Options for Mothers and Children
- Improving the Health Status of Children
- Interagency Collaboration and Cooperation
- Prevention Policy Issues and Concerns

Potential Summit products include:

- Recommendations to the Secretary of Health and Human Services and a report to the President addressing the adequacy of the national effort to prevent mental retardation and related disabilities

- A Summit Proceedings document

- A Guide for State Planning for the Prevention of Mental Retardation and Related Disabilities

The President's Committee on Mental Retardation acknowledges and extends appreciation to the following organizations and agencies for fiscal co-sponsorship of the Summit on the National Effort to Prevent Mental Retardation and Related Disabilities:

The Administration for Children, Youth and Families (ACYF)
U.S. Department of Health and Human Services

The Administration on Developmental Disabilities (ADD)
U.S. Department of Health and Human Services

The Administration on Aging (AoA)
U.S. Department of Health and Human Services

The American Academy of Pediatrics (AAP)

The Division of Birth Defects and Developmental Disabilities
Center for Environmental Health and Injury Control
Centers for Disease Control (CDC)
U.S. Department of Health and Human Services

The National Institute of Child Health and Human Development (NICHD)
National Institutes of Health
U.S. Department of Health and Human Services

The National Institute on Disability and Rehabilitation Research (NIDRR)
Office of Special Education and Rehabilitative Services
U.S. Department of Education

The Office of Disease Prevention and Health Promotion (ODPHP)
Office of the Assistant Secretary for Health
U.S. Department of Health and Human Services

The Office of Policy, Planning and Legislation (OPPL)
U.S. Department of Health and Human Services

The Social Security Administration (SSA)
U.S. Department of Health and Human Services

SUMMIT ON THE NATIONAL EFFORT TO PREVENT MENTAL RETARDATION AND RELATED DISABILITIES

THEME: Preventing the "New Morbidity" -- Improving Options for Mothers and Children

PROGRAM

Wednesday, February 6, 1991

8:30 am	Opening Session	AMBASSADOR ROOM
	Welcome	ALBERT L. ANDERSON, D.D.S. Vice Chairperson President's Committee on Mental Retardation
	Greetings	MARY SHEILA GALL Assistant Secretary for Human Development Services
	Opening Statements	WILLIAM K. HUMMER, M.D. Chairperson Prevention Subcommittee President's Committee on Mental Retardation
	Statement of Occasion "The Challenge"	HUGO MOSER, M.D. Director, Center for Research on Mental Retardation and Related Aspects of Human Development Kennedy Institute and Johns Hopkins University Baltimore, Maryland
9:00 am	Keynote Address-- "A National Prevention Strategy for Addressing Conditions that Negatively Affect Mothers and Children"	DUANE ALEXANDER, M.D. Director National Institute of Child Health and Human Development
9:50 am	REFRESHMENT BREAK	

10:00 am	**PANEL I**	AMBASSADOR ROOM
	What We Can and Must Do	
	CHRISTOPHER DeGRAW, M.D. Moderator Coordinator, Childrens and School Programs Office of Disease Prevention and Health Promotion	
10:05 am	Impact of the "New Morbidity" on Epidemiological Rates in Mental Retardation and Developmental Disabilities	GODFREY OAKLEY, M.D. Chief, Division of Birth Defects and Developmental Disabilities Centers for Disease Control
10:35 am	Healthy People 2000 Objectives for the Nation-- Impact on Persons with Mental Retardation and Related Disabilities	ASHLEY A. FILES Prevention Policy Advisor Office of Disease Prevention and Health Promotion Office of the Assistant Secretary for Health U.S. Department of Health and Human Services
11:05 am	A National Prevention Agenda including the Institute of Medicine (IOM) Study	ALLEN CROCKER, M.D. Director, Developmental Evaluation Clinic Children's Hospital Medical Center Boston, Massachusetts
11:35 am	*PANEL-AUDIENCE DIALOGUE*	
11:50 am	RECESS	

12:00 pm	CONFERENCE AWARDS LUNCHEON	EMPIRE ROOM
	LOUIS W. SULLIVAN, M.D. Speaker Secretary U.S. Department of Health and Human Services	
1:00 pm	**PANEL II**	AMBASSADOR ROOM
	Preventing the "New Morbidity"... Improving Options for Mothers and Children	
	M. DOREEN CROSER Moderator Executive Director American Association on Mental Retardation	
	A Model Approach for Preventing the "New Morbidity": Implications for a National Plan of Action	ALFRED BAUMEISTER, Ph.D. Director, John F. Kennedy Center for Research on Education and Human Development Peabody College, Vanderbilt University Nashville, Tennessee
	Effective Strategies for Preventing Mental Retardation and Related Disabilities Associated with Socioeconomic Conditions	EDWARD ZIGLER, Ph.D. Sterling Professor of Psychology Yale University New Haven, Connecticut
2:30 pm	*PANEL-AUDIENCE DIALOGUE*	
2:50 pm	REFRESHMENT BREAK	

3:00 pm	**PANEL III** Preventing the "New Morbidity"... Cooperative Multi-Agency Approaches and Options JAMES HARRELL Moderator Deputy Director Office of Disease Prevention and Health Promotion Office of the Assistant Secretary for Health	AMBASSADOR ROOM
3:05 pm	The Role of Developmental Disabilities Councils and Agencies in Planning for the Prevention of Mental Retardation Related Disabilities	DEBORAH McFADDEN Commissioner Administration on Developmental Disabilities
3:20 pm	Prevention Initiatives of the Administration for Children, Youth and Families to Address the Needs of Socioeconomically-Disadvantaged Mothers and Children	WADE HORN, Ph.D. Commissioner Administration for Children, Youth and Families
3:35 pm	Support Services of the Maternal and Child Health Bureau in Planning to Prevent Mental Retardation and Developmental Disabilities in Children	VINCE L. HUTCHINS, M,D. Acting Director Maternal and Child Health Bureau Public Health Service
3:50 pm	Social Security Initiatives that Impact the Lives of Families at Risk and Reduce Children's Morbidity	GWENDOLYN KING Commissioner Social Security Administration
4:05 pm	Rehabilitation Services Administration Options for Interagency Initiatives in Prevention and Rehabilitation	NELL CARNEY Commissioner Rehabilitation Services Administration Office of Special Education and Rehabilitative Services U.S. Department of Education

4:20 pm	Ameliorating the Effects of Mental Retardation and Related Disabilities in Aged Adults	JOYCE BERRY, Ph.D. U.S. Commissioner on Aging Office of Human Development Services U.S. Department of Health and Human Services
4:35 pm	NIDRR: Scope of Opportunity for Interagency Collaboration and Research in Mental Retardation	WILLIAM GRAVES, Ph.D. Director National Institute on Disability and Rehabilitation Research
4:50 pm	*PANEL-AUDIENCE DIALOGUE*	
5:00 pm	SHORT RECESS	

NOTE: Summit participants who desire a meeting place to conduct an evening workgroup session should see the Conference Planner, Laverdia Roach, before 3:00 0.m., Wednesday, February 6, 1991.

8:00 am PANEL IV — Diplomat ROOM

Improving the Health Status of Children

RUDY HOPMUTH
Moderator
Specialist in Services to Mentally Retarded Children
Maternal and Child Health Bureau
Public Health Service

8:05 am	Provisions of the Education of the Handicapped Act--Part H	MICHAEL E. VADER Deputy Assistant Secretary Office of Special Education and Rehabilitation Services
8:25 am	Office of Special Education Programs: Coordinated Service Delivery for a Changing Population of Students with Disabilities	JUDY SCHRAG, Ph.D. Director, Office of Special Education Programs U.S. Department of Education

8:45 am	The Impact of Substance Abuse and Teratogenic Factors on Child Development and Family Options	JUDY HOWARD, M.D. Professor of Clinical Pediatrics University of California at Los Angeles
9:05 am	Professional Preparation and Training to Meet the Needs of Mothers and Children with HIV Infection and AIDS	HERBERT J. COHEN, M.D. Professor of Pediatrics and Rehabilitation Medicine Director, Rose F. Kennedy Center University Affiliated Program Albert Einstein College of Medicine Bronx, New York
9:25 am	*PANEL-AUDIENCE DIALOGUE*	
9:40 am	REFRESHMENT BREAK	
9:50 am	Report of the World Summit on Children	JAMES M. SHERRY, M.D., Ph.D. Senior Advisor Program Division UNICEF
10:10 am	"Return Us The Children"--Societal Prerequisites	TRAVIS THOMPSON, Ph.D. Professor and Director Institute for Disability Studies University of Minnesota
10:30 am	*PANEL-AUDIENCE DIALOGUE*	
10:45 am	**PANEL V** **Exemplary State Planning to Prevent Mental Retardation and Related Disabilities Associated with Socioeconomic Conditions**	DIPLOMAT ROOM

MICHAEL J. ADAMS, Jr., M.D.
Moderator
Medical Epidemiologist
Division of Birth Defects and
Developmental Disabilities
Center for Environmental Health and
Injury Control
Public Health Service
Centers for Disease Control

10:50 am — GEORGE SCHMIDT, Ph.D.
Program Manager
Health and Rehabilitative Services
Tallahassee, Florida

11:10 am — ROGER CHAPMAN
Program Manager
Disability Prevention Program
Department of Public Health
Des Moines, Iowa

11:30 am — DEBORAH E. COHEN, Ph.D.
Director
Office for Prevention of
Mental Retardation and
Developmental Disabilities
Department of Human Services
Trenton, New Jersey

11:50 pm — RAYMOND PETERSON, M.D.
Director
San Diego Regional Center
San Diego, California

12:10 pm *PANEL-AUDIENCE DIALOGUE*

12:30 pm LUNCH (On Your Own)

1:30 pm CONCURRENT WORK GROUP SESSIONS

Work Group I	**CAPITOL**		
Application of the "New Morbidity Model" to Comprehensive State Planning	Leader	:	Alfred Baumeister, Ph.D.
	Resource Person	:	Edward Zigler, Ph.D.
	Facilitator	:	Sambhu N. Banik, Ph.D.
	Recorder	:	Pamela Coughlin
Work Group II	**EMBASSY**		
The Role of State and Federal Government in Facilitating Comprehensive State Planning	Leader	:	James Harrell
	Resource Persons	:	Ashley Files
			Deborah McFadden
	Facilitator	:	Ashot Mnatzakanian
	Recorder	:	Tacey Clausen
Work Group III	**CHAIRMAN**		
Strategies for Addressing Epidemiological Needs, Concerns and Interests	Leader	:	Godfrey Oakley, M.D.
	Resource Person	:	Michael Adams, M.D.
	Facilitator	:	Lila Thompson
	Recorder	:	George Bouthilet, Ph.D.
Work Group IV	**DIRECTORS**		
Successful Planning of Constituency Group, Interagency, and/or Intra-Agency Initiatives that Support Comprehensive State Planning	Leader	:	Sonya Oppenheimer, M.D.
	Resource Persons	:	John Pezzoli
			William Graves, Ph.D.
	Facilitator	:	Michael Vader
	Recorder	:	Kathy McGinley, Ph.D.
Work Group V	**CABINET**		
Practical Approaches to the Formulation and Endorsement of National Prevention Policy	Leader	:	Allen Crocker, M.D.
	Resource Person	:	Christopher DeGraw, M.D.
	Facilitators	:	Ethel Briggs
			William Jones, Ph.D.
	Recorder	:	Elaine Eklund

3:30 pm	REFRESHMENT BREAK	
3:40 pm	Closing Plenary	DIPLOMAT ROOM
	FRED KRAUSE Moderator Director Rehabilitation and Health Services Partners of the Americas Washington, D.C.	
3:45 pm	Work Group Reports and Recommendations to Speakers' Panel	Work Group Leaders
4:15 pm	Ratification of Recommendations	Summit Participants
4:45 pm	*SPEAKER-AUDIENCE DIALOGUE*	
5:00 pm	ADJOURNMENT	

APPENDIX B

Summit on the National Effort to Prevent Mental Retardation and Related Disabilities

EXHIBITORS

APPENDIX B
EXHIBITORS

PRE-SUMMIT RECEPTION AND EXHIBITS
FEATURING FEDERAL AND STATE PREVENTION EXHIBITS

Tuesday, February 5, 1991
6:30 pm - 8:30 pm

Omni Shoreham Hotel
2500 Connecticut Avenue, N.W.
Washington, D.C. 20008

EXHIBITORS

Department of Developmental Services Sacramento, California "Prevention 1995 - California's Future"	Mary Lou Hickman, M.D.
Elwyn, Inc. Elwyn, Pennsylvania	Carol Cherrix
National Association of Developmental Disabilities Councils Washington, D.C. "Forging a New Era"	Susan Ames Zierman
National Association for the Dually Diagnosed Kingston, New York	Michelle Jordan
National Institute on Disability Rehabilitation Research Washington, D.C.	James Doherty
North Carolina Office for Prevention Division of Maternal and Child Health Raleigh, North Carolina	Donna Scandlin

Office for Prevention of Mental Retardation and Developmental Disabilities North Brunswick, New Jersey	Glenna Gundell
National Parent Network on Disabilities Alexandria, Virginia "Outreach for Parents"	Patty Smith
Retarded Citizens/Atlanta Atlanta, Georgia "Prevention Education Exhibit"	Martha Towle
Social Security Administration Baltimore, Maryland	Lorraine Gunning
The National Center for Education in Maternal and Child Health Washington, D.C.	Maureen R. Seller

APPENDIX C

Summit on the National Effort to Prevent Mental Retardation and Related Disabilities

PROGRAM PARTICIPANTS

APPENDIX C
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APPENDIX D

Summit on the National Effort to Prevent Mental Retardation and Related Disabilities

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APPENDIX D
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APPENDIX E

Summit on the National Effort to Prevent Mental Retardation and Related Disabilities

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APPENDIX E
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APPENDIX F

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